Towards better outcomes in autism by addressing policy change

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Abbreviations

3DI	Developmental, Dimensional and Diagnostic Interview
AAH	Allocation aux Adultes Handicapés (France)
ABA	Applied Behaviour Analysis
ABT	Applied Behavioural Therapy
ADHD	Attention deficit hyperactivity disorder
ADI	Autism Diagnostic Interview
ADI-R	ADI-Revised
ADOS	Autism Diagnostic Observation Schedule
BMA	British Medical Association (UK)
CARS	Childhood Autism Rating Scale
CBT	Cognitive Behavioural Therapy
DIDR	Developmental and Individual Differences Relationship
DISCO	Diagnostic Interview for Social and Communication Disorders
DLA	Disability Living Allowance (UK)
DSM	Diagnostic and Statistical Manual
ESA	Employment and Support Allowance
ESDM	Early Start Denver Model
GI	Gastrointestinal
GP	General Practitioner
LSE	London School of Economics and Political Science
MDT	Multi-disciplinary Team
NICE	National Institute for Health and Care Excellence (UK)
OCD	Obsessive Compulsive Disorder
ODSP	Ontario Disability Support Program
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
PIP	Personal Independence Payment
PTSD	Post-traumatic Stress Disorder
QoL	Quality of Life
RDI	Relationship Development Intervention
SSGs	Social Skills Groups
SSI	Supplementary Security Income
SSRIs	Selective Serotonin Reuptake Inhibitors
TAE	Therapeutic Area Experts
UK	United Kingdom
USA	United States of America
VBT	Verbal Behavioural Therapy

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Executive summary

Background

Autistic individuals and their supporters are experiencing significant unmet need from health and social systems.

- There is urgent need to achieve better outcomes for autistic people and their supporters. At present, diagnostic processes are long and complicated, Quality of Life (QoL) is negatively affected, there are high out-of-pocket health and social care costs, and autism hinders employment opportunities for both autistic individuals and their supporters.

Improving outcomes for autistic individuals and their supporters requires early personalised interventions alongside supportive health and social systems.

- Improved outcomes require a paradigm shift from autism management to early assessment and diagnosis alongside personalised behavioural support. Additionally, lifelong social support systems including education, employment and accommodation should look to prioritise meaningful participation in society for autistic individuals.

Methods

This study used primary and secondary data collection to gather evidence on the social and economic impact of autism and the QoL of autistic individuals and their supporters. Prior to starting data collection, the team conducted interviews with the following stakeholders to understand the needs of various groups: a parent of an autistic child, a clinician working in the field and a representative from an autism charity. A systematic review was beyond the scope of our study and therefore, expanding on an initial narrative review provided by F. Hoffmann-La Roche was the most appropriate search methodology for the secondary data collection. Primary data collection was conducted by means of two web-surveys. The survey for autistic individuals and their supporters was based on a multidimensional questionnaire comprising seven sections which captured: i) diagnosis, ii) support and therapy after diagnosis, iii) education, iv) employment, v) accommodation, vi) QoL and vii) impact on supporters. The clinicians'

Geographic scope

The geographic scope of the research covers Canada, France, Germany, Italy, Spain, the United Kingdom and the United States.

survey captured evidence around diagnostic tools and pathways including clinical guidelines during and post assessment, accessibility and effectiveness of medical and social care, and the cost of these services.

Results

This study demonstrates that autism is associated with a significant socioeconomic impact generated by the high direct and indirect costs, the increased social isolation and discrimination and the poor QoL and social life outcomes exhibited by autistic individuals and their supporters. Given that autism is a lifelong disorder, the costs due to productivity losses both for the individuals themselves and for their supporters are overwhelmingly high, with significant implications for both the financial and physical wellbeing of autistic individuals and their families. There is a clear deterioration in the health outcomes of autistic individuals and their supporters in comparison to the rest of the population, with impact increasing in line with the severity of the disease and presence of mental health related concurrent conditions, particularly depression and anxiety. Our study revealed various determinants of the burden of autism on autistic individuals and their supporters. Key findings include:

Diagnostic and referral pathways

- Delays and shortcomings in the diagnostic process exist across countries. This is due to several factors, including the necessity of many visits to acquire a diagnosis, lack of standardised referral pathways and lack of specific training among the involved healthcare professionals for diagnostic assessment in cases where autism is suspected.
- Autistic adults experience unique autism-specific barriers to accessing care which are less likely to be addressed in modern healthcare systems such as limited autism specialists who treat adults, difficulty attending appointments because of the disruption in their routine and the sensory overload present at doctors' offices.

Quality of Life

- Factors driving QoL impairment in autistic individuals primarily include increased anxiety and depression, difficulty maintaining relationships, and difficulty communicating. Factors positively affecting QoL in autistic individuals are fulfilment from special abilities and creativity, greater ability to focus, and receiving or providing help from or to others, respectively.

Healthcare costs & Social services support

- Although state financed residential and social support services exist, they are often characterised by long waiting lists and/or regional unavailability. As a result, many autistic individuals and their families incur high out-of-pocket costs primarily for childcare, support workers, and privately funded therapy (e.g., behavioural therapy, counselling, and speech and language therapy).
- A significant proportion of medication utilisation in autism comes from antidepressants, anxiolytics, and antipsychotics used to manage mental health conditions associated with autism, while most autistic people do not receive any interventional therapies such as CBT.

Education

- Satisfaction with the educational environment and standards is poor among autistic individuals. This arises due to high rates of discrimination experienced by autistic individuals, especially in secondary school and especially for female individuals.
- High school teachers and educational professionals report a lack of support from their respective institutions to learn about autism.

Employment

- Poor employment outcomes among autistic employees are due to several factors including concurrent conditions, difficulty with communication and other social impairments, social discrimination, and a lack of understanding about autism in the workplace.
- For many autistic individuals it is not necessarily their autism causing a negative impact on their work life but primarily other reasons relating to discrimination in the workplace, colleagues and managers who are unwilling to understand and accommodate autistic individuals' requirements, and lack of support in disclosing autism in the workplace.

Supporters

- Supporters typically have decreased work force involvement, missing eight days of work per month on average due to supporters' responsibilities. The employment related strain is further escalated by the limited support provided for these families by their employers.
- Poor QoL among autistic individuals' supporters is generated by mental health issues, social exclusion and isolation and the emotional stress arising from the constant feeling of fear about the future of the person they care for or the feeling that the person they care for is dependent on them.

Recommendations

Our results, coupled with existing findings from the literature confirm that there is an urgent need to achieve better outcomes for autistic people and their supporters. Evidence suggests that this is possible if policy makers address a series of issues to secure the following goals:

1 ***Shift the paradigm in autism management towards provision of early assessment and diagnosis.***

- Ensure wider coverage of diagnostic services and evaluations in cases where autism is suspected: often, high-cost diagnostic services in autism need to be funded privately, leading to a high rate of foregone appointments.
- Minimize the number of visits required for diagnostic assessments to avoid diagnostic delays: the plethora of healthcare professionals involved in autism diagnosis, and the respective multiple visits required for assessments often deters individuals from seeking diagnostic services due to the stress and emotional exhaustion associated with arranging and attending doctors' appointments.
- Raise awareness among healthcare professionals and appointment coordinators about the sensory and emotional challenges that doctors' offices present for autistic people and about the need to accommodate visits accordingly to avoid missed or postponed appointments.

2 *Tailor interventions and behavioural support mechanisms based on a person-centred approach that addresses the personalised needs of autistic individuals and their supporters.*

- Interventional therapies and behavioural support in autism should focus on strengthening individuals' performance in domains that have a positive impact on their QoL, such as encouraging each individual's special abilities & creative skills.
- Treating autism associated mental health conditions through targeted interventional therapies is high priority in autism management. This can help reduce overprescribing and overspending on psychotropic medication used to manage concurrent mental health conditions and prevent side-effects associated with long-term use of these drugs.

3 *Re-define the priorities of social support mechanisms, while enhancing the availability and quality of existing schemes.*

- Enable people to have control over their lives, education, and accommodation arrangements, through supported living and innovative housing solutions, and support services to direct autistic children in deciding which education pathway they should follow.
- Ensure that state-funded day services provide both timely and quality care and support, through adequately trained people, while also being readily accessible both in terms of geographic location and regional access regulations or bureaucracies.
- Secure local funding and accessibility/availability of: i) public special education institutions or programs and social policies, ii) personalised support measures for autistic pupils whether in mainstream or special education and iii) practice guidelines to guide the implementation of systems for young autistic people, transitioning from school or college to adulthood.

4 *Restructure autism specific training and guidelines for clinicians to optimize the diagnostic and clinical care outcomes for autistic individuals.*

- Set out incentivisation mechanisms for clinicians to follow autism diagnostic guidelines and hence, improve diagnostic pathways and the quality of clinical care provided in autism.
- Increased responsiveness of health care systems and adaptation of guidelines to the most updated evidence on autism is essential for improved diagnostic outcomes but

also for strengthening interventions and monitoring practices in autism management and hence, avoiding inappropriate over-prescribing for autistic individuals.

- Establish adult and gender-specific diagnostic protocols in routine clinical practice and implement specific training and referral guidelines for cases with distinct forms of and/or combination of impaired mood dysregulation and anxiety to facilitate accurate and timely diagnoses in individuals with suspected autism.

5 ***Educate society, schools, and workplaces on the requirements of autistic individuals and involve these entities in collaboratively achieving better outcomes in autism.***

- Foster greater awareness and understanding of autism among workplaces and employers to achieve better employment prospects for autistic individuals.
- Introduce autism awareness activities for young children, to help prevent the discrimination currently experienced by autistic children within the educational environment.
- Improved training and support for teachers working with autistic children and adolescents is also essential for the improvement of educational outcomes in autism.
- Collaboration between the educational, workplace and social care sectors is essential to form integrated transition pathways for autistic children/adolescents, to support smooth transition to adulthood. Transition planning activities should cover all areas of service provision, including housing and employment support.

6 ***Measure meaningful outcomes and generate further robust evidence to inform decision making in the management of autism.***

- Perform real world studies based on national registries to measure the benefit of early diagnosis and hence, early intervention on the long-term outcomes for autistic individuals and their families. This is important because despite the suggested benefit of early, integrated developmental and behavioural intervention on the long-term prognosis in autism there is yet no quantifiable evidence of this benefit.
- Measure and evaluate health outcomes on domains that matter the most for autistic individuals and their supporters. For autistic individuals, these should focus on measuring outcomes on mental health state and satisfaction with social interactions and relationships and for supporters, outcomes on their emotional health and social life status. However, given the large heterogeneity of autism manifestations and characteristics among the autism community, the above aspects should be considered

and measured in the context of a more personalised outcomes measurement approach for each individual.

- Multi-stakeholder engagement and collaboration in autism relevant evaluation research is critical to ensure measurement of meaningful outcomes in autism; involvement of supporters is specifically important to provide a shared understanding on the various levels of intertwined outcomes in autism that add value both for autistic individuals and their families.

Conclusions

Findings from our study, combined with existing findings from the literature provide a strong evidence base for the unmet need currently present in autism. Inefficiencies in diagnostic processes and interventional therapies, poor employment prospects and the inability to live independently represent a substantial and growing challenge for some autistic individuals. Additionally, the increased emotional stress and productivity losses exhibited by the supporters of these individuals further contribute to the broader socioeconomic implications of autism.

A fundamental step towards improved long-term outcomes in autism is provision of early diagnosis and assessment. Nevertheless, further evidence from pragmatic studies based on data from national registries is needed to quantify the magnitude of this benefit for autistic individuals, their families and society overall. Additionally, governments and healthcare systems should centre their efforts specifically on adapting infrastructure, training, and clinical guidelines in autism. Funding efficient, person-specific interventions is also essential to provide the best health outcomes possible according to the specific physical, social and behavioural needs of every autistic individual. Finally, the effective collaboration of society, schools, and workplaces is paramount for the smooth transitioning of autistic children and adolescents to adulthood including securing better living arrangements, employment options and achieving a sense of meaningful participation in society for every autistic individual.

The policy recommendations arising from this study highlight that improved outcomes in autism are feasible if policy makers address the key determinants of burden, as identified in our study, for autistic individuals and their families. Of course, as our study was conducted in the early stages of the COVID-19 pandemic, it does not necessarily capture any additional burden arising from COVID-19 for autistic individuals and their families and therefore, more recent, real-world evidence is essential to elucidate the full social and economic impact of autism across countries as it is currently shaped in a post-pandemic environment. Similarly, the findings and recommendations presented in this report should be interpreted with caution, given the sampling limitations of our study. The uneven geographical spread of the respondents, and uneven representation of different autism severity levels in our study sample, mean that our findings may not be entirely representative of the true environment, experiences and autism care practices followed across the study countries or the true outcomes observed in a largely heterogeneous international population of autistic individuals.

1. Background & Objectives

Autism is a neurodevelopmental disorder that affects communication and behaviour. Whilst there is variation in the way it affects people, characteristic features include "a variable mixture of impaired capacity for reciprocal socio-communicative interaction and a restricted, stereotyped repetitive repertoire of interests and activities" (WHO, 2013) that could affect ability to function in education, employment and other areas of life (National Institute of Mental Health, 2018). Autism was first described as a syndrome that affected children's "ability to relate themselves in the ordinary way to people and situations from the beginning of life" (Kanner, 1943) and was originally thought to be a form of schizophrenia (National Autism Center, n.d.; Zeldovich, 2018), although later the Diagnostic and Statistical Manual (DSM)-3 created a boundary between autism and schizophrenia (King, Navot, Bernier, & Webb, 2014). Additional diagnoses of Asperger's disorder, childhood disintegrative disorder, Rett's syndrome, and pervasive developmental disorder not otherwise specified (PDD-NOS) were also added to the manual (King et al., 2014). In the most recent DSM-5 these categories were combined into Autism Spectrum Disorder (King et al., 2014). There are multiple autism subtypes influenced by a combination of genetic and environmental factors. The 'spectrum' aspect of the disorder reflects the fact that each autistic person has a different experience of the disorder, encompassing the above distinct diagnoses. As such, there is significant heterogeneity in the manifestations and characteristics of autism among the international autism community and thus, no universally accepted description of autism.

Autism is a lifelong disorder that can significantly compromise the emotional, mental, physical, and financial wellbeing of autistic individuals and their families. Estimating the impact and value of policy and therapeutic interventions in autism involves the exploration of the key determinants of burden for those diagnosed and their supporters, including direct medical costs, productivity losses and intangible costs arising from delayed access to care, emotional and Quality of Life burden.

Terminology-related disagreements stem from this variation in experience as well as the growing disability rights and neurodiversity movements and the lack of consensus amongst the scientific community as to how best to describe autism (Kenny et al., 2016).

The World Health Organization estimates a global median autism prevalence of 1 in 160 children, with reported prevalence varying across countries and studies (WHO, 2013). Childhood autism prevalence studies in North America predict levels to be around 1 in 44 in the United States (USA) (Center for Disease Control, 2021) and 1 in 66 in Canada (Government of Canada, 2018). In Europe prevalence has been found to be lower, ranging from 1 in 100 in the United Kingdom (UK) (BMA, 2020), to 1 in 274 in France (van Bakel et al., 2015). There is also variation in prevalence between children and adults, most likely due to late diagnosis in many individuals. For example, in the USA, it was estimated that in 2020 1 in 45 adults were autistic (Dietz, Rose, McArthur, & Maenner, 2020) compared to 1 in 54 children (Center for Disease Control, 2020). In the UK, this figure was estimated to be 1 in 90 adults (NICE, 2020) compared to 1 in 100 children (BMA, 2020). There is also variation in prevalence estimates between males and females. For many years the "4:1" ratio was one of the most replicated findings in autism (Halladay et al., 2015), indicating that males are four times as likely as women to be diagnosed with autism. More recent research, though, suggests that this may be due to diagnostic differences and differences in the presentation of autism in males and females (Halladay et al., 2015).

Rates of autism have been increasing, likely due to expanded diagnostic criteria, heightened awareness of autism, diagnosis at earlier ages, and the recognition that autism is a lifelong condition (Matson & Kozlowski, 2011). As autism prevalence continues to rise, so does the associated direct and indirect financial impact for individuals and systems. Families tend to bear most of the financial and care responsibilities, as autistic children are typically less likely to have both parents working than children without autism, resulting in a roughly 30% cut in family earnings (Cidav, Marcus, & Mandell, 2012).

In the USA, the estimated lifetime cost of supporting an autistic individual for health and social service systems is $1.4 million (Buescher, Cidav, Knapp, & Mandell, 2014). Within this figure, annual healthcare costs for autistic individuals increase from between $6,467 (age 0-5) and $9,053 (age 6-17) respectively to $13,580 in adulthood (Buescher et al., 2014). Social and community service costs alone can amount to $38,105 in ages 0-5, with special education being the highest contributor to these costs (Buescher et al., 2014). Similarly, in the UK, the annual cost of education for an autistic child is £10,326 ($19,801) between the ages of four and 11, increasing to £28,606 ($54,854) between the ages of 12 and 17 (Rogge & Janssen, 2019). Special education has also been reported to be the highest contributor to direct costs for autistic people and their families across European Union (EU) countries (ASDEU, 2018).

Additionally, the diagnostic process is often affected by long waiting times, visits to multiple specialists and a battery of diagnostic tests. Alongside significant direct medical costs the drawn out diagnosis process can delay access to suitable education and lead to undue stress for the families and individuals which can contribute to an increased financial and socioeconomic burden in the long-term (BMA, 2019).

1.1. Report aims & objectives

Despite the availability of literature on the prevalence and financial implications of autism, an evidence gap remains in the determinants of the burden and increased unmet need experienced by autistic individuals and their families. As such, this study aims to build a strong policy case for the need to understand the drivers of the social and economic impact of autism across countries. We aim to explore the factors that influence differing prevalence, diagnostic and treatment pathways, and social care systems in the study countries as well as the true value of interventions across the lifespan. Maximising our understanding of the experiences of autistic individuals, their supporters, and physicians will allow us to make well-informed policy recommendations to improve clinical and social care mechanisms in autism and hence, achieve better outcomes in autism management. Ultimately, we aim to understand the value of a shift in focus from symptom management to a paradigm of maximizing human potential in autism.

Report aims

1. Build a strong policy case for the need to understand the drivers of the social and economic impact of autism across countries.

2. Explore the factors that determine differences in the prevalence, diagnostic pathways, and social care systems across the study countries, as well as the true value of intervention across the lifespan.

3. Maximise our understanding of the experiences of autistic individuals, their families and physicians to make policy recommendations towards improved outcomes in autism management and care.

2. Methods

This study encompasses primary and secondary data collection for the identification of evidence on the social and economic impact of autistic individuals and their supporters across the geographic scope of the study: Canada, France, Germany, Italy, Spain, the UK, and the USA. Primary data was collected through two surveys: one for autistic individuals, which also included a dedicated section for their supporters and one for clinicians involved in autism assessment and treatment. The study protocol for primary data collection was submitted to and approved by the London School of Economics (LSE) Research Ethics Committee.

Prior to primary and secondary data collection, the team conducted interviews with the following stakeholders to understand the needs of various groups: a parent of an autistic child, a clinician working in the field and a representative from an autism charity. The findings from these interviews aided our understanding of autism, enabled engagement with the topic in a respectful manner and provided a meaningful contribution which is useful to the community. As part of this, we recognise language has the power to reflect and shape people’s views of autism and the importance of carefully considering the language in use. We are aware of the disagreements related to the preference for either "person-first" (e.g., person with autism) or "condition-first" (e.g., autistic person) language amongst the autism community and have been advised by the above-mentioned groups of stakeholders to use condition first language. In this report, “condition” is meant in a non-negative way, and we aim to do our best to respect all individuals’ experiences of autism.

2.1. Literature review

The secondary data collection built on knowledge from datasets provided by F. Hoffmann-La Roche, including a policy narrative review from 2018 that included 656 literature sources around autism prevalence, medical costs, social challenges, and barriers in access to education, treatment and services autistic individuals face as well as the role of informal supporters. Additionally, this narrative review summarized estimates for the financial consequences of autism.

Building on this narrative review, the literature review conducted for this study sought to investigate further the diagnostic experiences, clinical and social care support mechanisms, the financial impact, and Quality of Life (QoL) of autistic individuals and those close to them, across the study countries. The scope of the literature review was limited to the aforementioned topics to align with the respective themes of the surveys (see sections 2.2

and 2.3). Several databases were searched, including, among others, Google Scholar, Scopus, Medline and the Social Science Citation Index, and relevant peer-reviewed literature, working papers, government and multi-national organization reports, and statements from patient associations found within those databases were reviewed. In total, 135 sources were identified and reviewed for this study in addition to the 656 sources from the narrative review. A full systematic literature review was beyond the scope of our study and therefore, a comprehensive literature review expanding on the initial narrative review was deemed to be the most suitable search methodology.

2.2. Survey for autistic individuals and their supporters

We conducted a retrospective, web-based survey of autistic individuals aged 18 and over, autistic individuals under 18 accompanied during the survey by someone aged 18 or over, and individuals over 18 who care for autistic individuals of any age. The survey was based on a multidimensional questionnaire comprising seven sections: i) diagnosis, ii) support and therapy after diagnosis, iii) education, iv) employment, v) accommodation, vi) QoL and vii) impact on supporters.

The survey was reviewed by six autistic individuals and seven supporters through the Autistica (a UK autism research charity) Insight Group to ensure questions were comprehensive and appropriate in both content and language. Their valuable feedback and input on the draft survey was incorporated into the final version.

The questionnaire was translated and made available in five languages including English, German, French, Italian, and Spanish. 28 patient organisations across the seven countries were invited via e-mail to voluntarily share the questionnaire with their network of patients and supporters. Additionally, relevant reddit discussion boards and national autism forums were also used to distribute the survey link to autism communities. These online communities were chosen because of their global nature, targeted content, and willingness to distribute surveys. Three discussion boards within the reddit community allowed the survey to be shared with their members: r/Autism, r/Neurodiversity, and r/AutismTranslated.

Eligibility for participation required respondents to be a resident in one of the seven countries in scope. To ensure anonymity, questionnaire responses carried no identifying information. Preceding the actual survey questions, an online information sheet described the objectives of the survey and processes related to data confidentiality. All participants were asked to provide online written informed consent to indicate their understanding of the study conditions and their agreement to participate. The survey was hosted online on Qualtrics® under an LSE-verified account and remained open for eight weeks between October 2020 and December 2020.

2.3. Survey for clinicians

A second survey targeted professionals involved in autism assessment and post-diagnostic support. The survey sought to capture expert knowledge of the impact of medical and behavioural interventions on QoL, financial security, education and employment for autistic people and their families. Themes covered by the survey included the timeline for diagnosis and support, diagnostic tools and pathways including clinical guidelines during and post assessment, accessibility and effectiveness of medical and social care, and the cost of these services.

Participants for this survey were targeted through LSE's network from the Autism Europe Conference, F. Hoffmann-La Roche Therapeutic Area Experts (TAE), and expert witness lists identified through Google. Clinicians were invited via email to participate in the survey. Responses in the USA were particularly low, so we expanded the scope of clinicians to include nurses in the USA only. The clinician survey was not circulated in online forums. The survey was hosted online on Qualtrics® under an LSE-verified account and remained open for 34 weeks between May 2020 and December 2020.

2.4. Synthesis of results

Primary and secondary data were analysed thematically across the following topics: diagnostic process and clinical care after diagnosis, costs to individuals and their families, social services support, and impact on QoL and work productivity for autistic individuals and their supporters. This allowed comparability of the survey results with literature findings. More precisely, survey findings were compared across countries, while additional comparisons and benchmarking between survey results and literature review findings were also performed across the study countries. Policy gaps were identified via comparison of the current state of care and support mechanisms in autism to the 'ideal state'. The 'ideal state' would be one where autistic individuals have prompt and equal access to diagnostic support and clinical care as well as sufficient post-diagnosis support in the form of educational, employment and housing opportunities. A set of related policy recommendations were then developed.

3. Results

3.1. Survey response rate & sample characteristics

A total of 833 surveys were initiated across all study countries, of which 451 surveys were adequately completed for analysis. Of the 451 surveys, 276 (61%) were completed by "an autistic person", 167 (37%) by "a supporter, on behalf of an autistic person" and 8 (1.8%) by "an autistic person with the support of an assistant". Responses were from the UK (n=287, 64%), Spain (n=40, 9%), Germany (n=36, 8%), France (n=32, 7%), USA (n=30, 6%), Italy (n=18, 4%), and Canada (n=8, 2%).

Most respondents[1] were female[2] (49%) and single (56%). The average respondent age was 36 (±17) years, with a mean age at diagnosis of 27 (±19) years (Table 1). We measured level of verbal communication ability as a proxy for 'severity' of autism. 53% (n=241) of respondents had no problem communicating verbally, 39% (n=176) had some difficulty in verbal communication and 5.5% (n=25) said they were completely non-verbal (Table 1). In our study, gender prevalence is not consistent with the 4:1 male to female ratio described in the literature (Lockwood Estrin, Milner, Spain, Happé, & Colvert, 2020) indicating that this ratio may not always be representative of the true gender prevalence in autism. This discrepancy could also arise due to potential biases around this ratio, including sex-specific characteristics such as males exhibiting a higher prevalence of other developmental conditions compared to females (Halladay et al., 2015) or females being able to 'mask' autism related characteristics (NHS, 2019). In addition, given that more than half of our study participants were from the UK, the larger group of females observed in our study is in line with more recent findings from the UK demonstrating an increased incidence of diagnosis in adult females (Russell et al., 2022).

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[1] *As we captured information from both autistic individuals and supporters on behalf of autistic individuals, the word 'respondent' corresponds to the autistic individual for which the survey was filled in and not the physical respondent (i.e., in cases where supporters responded on the behalf of an autistic individual).*

[2] *Gender is classified as "Male", "Female" and "Other identity". "Other identity" comprises "Non-binary", "Male (gender different to gender assigned at birth)", "Female (gender different to gender assigned at birth)", "Prefer not to answer" and "Other (please specify).*

Table 1. Sample demographic and QoL characteristics.

	Canada (n=8)	France (n=32)	Germany (n=36)	Italy (n=18)	Spain (n=40)	UK (n=287)	USA (n=30)	Total (n=451)
Demographics								
Respondent, n (%)								
• Autistic person	6 (75%)	22 (68.7%)	25 (69.4%)	4 (22.2%)	4 (10%)	193 (67.2%)	22 (73.3%)	276 (61.2%)
• Supporter, on behalf of an autistic person	2 (25%)	9 (28.1%)	10 (27.7%)	13 (72.2%)	35 (87.5%)	90 (31.3%)	8 (26.6%)	167 (37%)
• Autistic person with support of an assistant	0%	1 (3.1%)	1 (2.7%)	1 (5.5%)	1 (2.5%)	4 (1.4%)	0%	8 (1.8%)
Age, mean (SD)	36 (12)	36 (15)	33 (16)	34 (13)	29 (14)	37 (17)	39 (16)	36 (17)
Adults, n (%)	8 (100%)	29 (90.6%)	29 (80.5%)	16 (88.9%)	30 (75%)	240 (83.6%)	27 (90%)	379 (84%)
Age at diagnosis, mean (SD)	28 (19)	29 (14)	25 (18)	13 (14)	9 (12)	30 (18)	23 (19)	27 (19)
Gender, n (%)								
• Female	3 (37.5%)	22 (68.7%)	19 (52.7%)	8 (44.4%)	12 (30%)	138 (48%)	19 (63.3%)	221 (49%)
• Male	5 (62.5%)	8 (25%)	10 (27.7%)	10 (55.5%)	28 (70%)	126 (43.9%)	11 (36.6%)	198 (43.9%)
• Other*	0%	2 (6.2%)	7 (19.4%)	0%	0%	23 (8%)	0%	32 (7%)
Marital status, n (%)								
• Single	4 (50%)	16 (50%)	17 (47.2%)	10 (55.5%)	29 (72.5%)	159 (55.4%)	16 (53.3%)	251(55.6%)
• Married or cohabiting	3 (37.5%)	11 (34.3%)	8 (22.2%)	7 (38.8%)	10 (25%)	92 (32%)	13 (43.3%)	144 (31.9%)
• Divorced	1 (12.5%)	3 (9.3%)	2 (5.5%)	0%	0%	13 (4.5%)	0%	19 (4.2%)
• Separated	0%	1 (3.1%)	1 (2.7%)	0%	0%	6 (2%)	0%	8 (1.7%)
• Widowed	0%	0%	0%	0%	0%	4 (1.3%)	1 (3.3%)	5 (1.1%)
• Other	0%	1 (3.1%)	8 (22.2%)	1 (5.5%)	1 (2.5%)	7 (2.4%)	0%	24 (5.3%)
Verbal communication, n (%)								
• No problem	6 (75%)	15 (46.9%)	17 (47.2%)	10 (55.5%)	11 (27.5%)	161 (56%)	21 (70%)	241 (53.4%)
• Some difficulty	2 (25%)	15 (46.9%)	13 (36.1%)	7 (38.8%)	20 (50%)	111 (38.6%)	8 (26.6%)	176 (39%)
• Completely non-verbal	0%	2 (6.2%)	3 (8.3%)	1 (5.5%)	9 (22.5%)	9 (3.1%)	1 (3.3%)	25 (5.5%)

• Prefer not to say	0%	0%	3 (8.3%)	0%	0%	6 (2%)	0%	9 (2%)
QoL characteristics								
Physical health from 0-100, mean (SD)	75 (16)	53 (29)	67 (21)	68 (21)	73 (20)	63 (25)	76 (24)	65 (25)
Mental health from 0-100, mean (SD)	64 (25)	49 (25)	54 (22)	66 (24)	64 (24)	50 (27)	75 (20)	54 (27)
Impact on daily activities from 0-10, mean	5.8	5.9	5.8	4.5	5.9	5.7	4.7	5.6
Satisfaction with diagnostic process from 0-10, mean (SD)	6.8 (3.5)	5 (3.6)	5.9 (3.2)	7 (2.7)	6.8 (2.9)	6.3 (3.2)	7.5 (3.1)	6.4 (3.2)
	Canada (n=8)	**France (n=32)**	**Germany (n=35)**	**Italy (n=17)**	**Spain (n=39)**	**UK (n=284)**	**USA (n=29)**	**Total (n=444)**
Negative impact on QoL and well-being, n (%)								
• A great deal	2 (25%)	16 (50%)	7 (20%)	7 (41.1%)	13 (33.3%)	157 (55.3%)	8 (28%)	210 (47%)
• Somewhat	3 (37.5%)	11 (34.3%)	12 (34.3%)	2 (11.8%)	7 (18%)	71 (25%)	9 (31%)	115 (26%)
• A little	2 (25%)	4 (12.5%)	4 (11.4%)	4 (23.5%)	9 (23%)	32 (11.2%)	7 (24%)	62 (14%)
• Not at all	0%	0%	4 (11.4%)	2 (11.8%)	7 (18%)	7 (2.4%)	4 (14%)	24 (5%)
• I don’t know	1 (12.5%)	1 (3.1%)	8 (22.8%)	2 (11.8%)	3 (7.7%)	17 (6%)	1 (3%)	33 (7%)
	Canada (n=7)	**France (n=32)**	**Germany (n=35)**	**Italy (n=18)**	**Spain (n=37)**	**UK (n=280)**	**USA (n=30)**	**Total (n=439)**
Negative impact on social life, n (%)								
• A great deal	4 (57.1%)	22 (68.8%)	20 (57.1%)	7 (38.8%)	16 (43.2%)	198 (70.7%)	14 (46.7%)	281 (64%)
• Somewhat	2 (28.6%)	5 (15.6%)	9 (25.7%)	3 (16.7%)	7 (18.9%)	54 (19.3%)	7 (23.3%)	87 (19.8%)
• A little	0%	3 (9.3%)	2 (5.7%)	3 (16.7%)	8 (21.6%)	15 (5.3%)	3 (10%)	34 (7.7%)
• Not at all	0%	2 (6.2%)	1 (2.8%)	3 (16.7%)	5 (13.5%)	10 (3.6%)	5 (16.7%)	26 (5.9%)
• I don’t know	1 (14.3%)	0%	3 (8.6%)	2 (11.1%)	1 (2.7%)	3 (1%)	1 (3.3%)	11 (2.5%)

Key: * “Other” gender category indicates; “Non-binary”, Male (gender different to gender assigned at birth)”, Female (gender different to gender assigned at birth)”, Prefer not to answer” and “Other (please specify).

Note: n= Number of respondents/responses, SD= Standard Deviation

4. Diagnosis

4.1. Concurrent conditions and additional diagnoses

The most common additional conditions autistic individuals have been diagnosed with include anxiety (55%, n=250), depression (40%, n=182), learning disability (e.g., dyslexia) (19%, n=86), gastrointestinal (GI) disorders (18%, n=83) and attention deficit hyperactivity disorder (ADHD) (18%, n=80). Less common diagnosed concurrent conditions reported in the survey included musculoskeletal issues (12%, n=54), epilepsy (5%, n=24), diabetes (4%, n=17) and cardiovascular disease (3%, n=13). Finally, 11% (n=51) reported no additional diagnoses or concurrent conditions, whereas 35% (n=156) reported several "other conditions", including anorexia, and eating disorders, Post Traumatic Stress Disorder (PTSD), bipolar disorder, obsessive compulsive disorder (OCD), dyspraxia, sensory processing disorder and migraines.

Our findings are consistent with literature from Canada, Spain, the UK, and the USA, which suggests that the most common additional diagnoses in autism include mood or anxiety disorders and ADHD, and these are on average reported by about 40% to 50% of autistic adult or children/adolescent study populations. For example, in Canada estimations are that 42% of children and adolescents with "higher-functioning" autism and Asperger syndrome experience anxiety (Dudley & Emery, 2014). A Spanish study concluded that more than 50% of autistic children and adolescents present with at least one concurrent condition, with ADHD and anxiety disorders being the most prevalent (Rosa, Puig, Lázaro, & Calvo, 2016). In the UK, about 40% of autistic individuals have at least two mental health problems mainly anxiety and ADHD (Autistica, n.d.; National Collaborating Centre for Mental Health & NICE, 2021) and up to 70% of autistic individuals have at least one mental health disorder. Finally, in the USA, between 34% to 69% of autistic individuals suffer from co-occurring psychiatric disorders and symptoms (Davignon, Qian, Massolo, & Croen, 2018; Office of Autism Research Coordination, 2016), primarily mood (57%) and anxiety (50 %) disorders, and ADHD (39 %) (Brookman-Frazee, Stadnick, Chlebowski, Baker-Ericzén, & Ganger, 2018; Buck et al., 2014; Houghton, Ong, & Bolognani, 2017; Joshi et al., 2013). In terms of non-psychiatric concurrent conditions, literature corroborates the additional diagnoses observed in our study, although their respective prevalence differs potentially due to sampling sizes. For example, an American study of adult autistic individuals showed that the most common non-psychiatric concurrent conditions included nutritional disorders (38%), cardiovascular disease (37%), GI disorders

(35%), epilepsy (12%), diabetes (8%) and musculoskeletal disorders (7%) (Vohra, Madhavan, & Sambamoorthi, 2017).

4.2. Diagnostic & referral pathways

In our study, the average age when first features of autism were noticed was 19.7 (±19.1) years across all countries, with a median age of 11 years, and the average age when a diagnosis was received was 26.5 (±18.5) years, with a median age of 25 years. Great variation was observed across countries on the average reported age of first features of autism and age of diagnosis, ranging from 22.6 (±19.9) and 23.1 (±18.9) respectively in the USA to 6.4 (±10.8) and 9.1 (±11.7) respectively in Spain (Figure 1). Despite literature suggesting that the first features of autism usually appear in the first two to five years of life and is typically diagnosed in young children (National Institute of Mental Health, 2018), our results highlight that, for many autistic individuals, diagnosis does not come until adulthood. Considering the significantly larger cohort of participants from the UK compared to other countries in our study, the older average age of diagnosis observed in our study is consistent with recent evidence from the UK reporting an increased incidence of diagnosis in adulthood (Russell et al., 2022).

Additionally, the significant time lag between the first features of autism becoming apparent and receipt of a diagnosis shown in our study is consistent with literature from Germany suggesting an average gap of nearly five years from first parental concerns to diagnosis (Höfer et al., 2019).

Overall, across the study sample, first concerns about autism were raised by autistic individuals or their family primarily with a General Practitioner (GP) or family doctor (28%, n=120), and a mental health professional (18.6%, n=80). In some countries though, first concerns about autism were raised with a paediatrician (e.g., in Italy; 37.5%, n=6, Spain; 35.3%, n=12 and Germany; 18.1%, n=6) (Table 2). Country specific findings on the professionals involved in autism diagnosis from Germany and Italy align with our findings. In Germany, there are no standardised pathways for diagnostic assessment in cases where autism is suspected, while paediatricians are among the first point of contact for parents of children with mental health concerns (Höfer et al., 2019). In Italy, despite the fact that there are more public than private health centers that report having the ability to diagnose autism, autism is still more frequently diagnosed in the private sector (Borgi, Ambrosio, Cordella, Chiarotti, & Venerosi, 2019). Overall, an official autism diagnosis was made mainly by a psychologist (42.6%, n=183), a psychiatrist (26.3%, n=113) or a multi-disciplinary team (MDT) (24%, n=103), with little to no fluctuation between countries on the key healthcare professionals involved in diagnosis (Table 2).

Furthermore, across all countries, the average time between first referral and diagnosis was 23 (±60) months, ranging from 4.5 (±4) months in Italy to 34 (±122) months in the USA (Table 2). The great cross-country variation found between first referral and diagnosis is also highlighted in the literature. For example, in the UK, an average waiting time between initial consultation and autism diagnosis of 3.5 years is reported (Crane, Chester, Goddard, Henry, & Hill, 2016), while in Scotland shorter delays have been observed with most cases taking around four months between initial referral and diagnosis (BMA, 2019). Similarly, in Canada this gap is reported to be around seven months (Penner, Anagnostou, & Ungar, 2018).

Finally, on a self-rated scale of satisfaction with the process of autism diagnosis from 0 (not at all satisfied) to 10 (very satisfied), it was demonstrated that average satisfaction score was 6.4 across all countries, ranging from 5 in France to 7.5 in the USA (Figure 1). A discrepancy was observed between the satisfaction score reported by autistic individuals themselves vs. supporters responding on behalf of autistic individuals, scoring 6.8 and 5.8 respectively. Predominant factors influencing satisfaction levels around the diagnostic process included "the time it took to get a diagnosis" (22%, n=99), "difficulties involved with finding a professional to help or diagnose" (17%, n=75) and "concerns not taken seriously by health care professional" (15%, n=66), followed by "the information received at diagnosis" (14%, n=62), "getting an initial referral (14%, n=62), "the way autistic person is treated by the diagnosing professional" (11%, n=49) and "paying out-of-pocket to receive a diagnosis" (5%, n=21). The above-mentioned concerns are consistent with literature from France, Germany, and USA. For example, a German study reported that overall, only about 38% of supporters of autistic children were satisfied with the diagnostic process, primarily due to diagnostic delays (Höfer et al., 2019). Similarly, in France, too many parents are reported to be victims of misdiagnosis and therapeutic shortcomings that delay the proper diagnosis and then the care process (Autisme France, 2015; Chamak, Bonniau, Oudaya, & Ehrenberg, 2011). To this end, France introduced a plan for autism care targeting earlier diagnosis, more support for autistic individuals and their families, and greater research and education funding (Ochs, 2018). Nevertheless, our findings still showcase a significant gap between age at first features of autism and age at diagnosis in France.

Key findings on the diagnostic and referral pathways

- Anxiety and depression were key concurrent conditions among our study population.
- Based on this study, age at which features of autism were first noticed and age at diagnosis were 19.7 (±19.1) and 26.5 (±18.5) years, respectively.
- Average time between first referral and diagnosis received was 23 (±60) months, with great variation across countries.
- First features of autism were most often raised with a GP and a mental health professional.
- On a satisfaction scale from 0 (not at all satisfied) to 10 (very satisfied), average satisfaction with the diagnostic process was 6.4. Key factors influencing this score were the time it took to get a diagnosis and difficulties involved with finding a professional to help or diagnose.

Figure 1. A comparative graph of age when first features of autism were noticed vs. age when diagnosis was received, and overall satisfaction with the diagnostic process across countries.

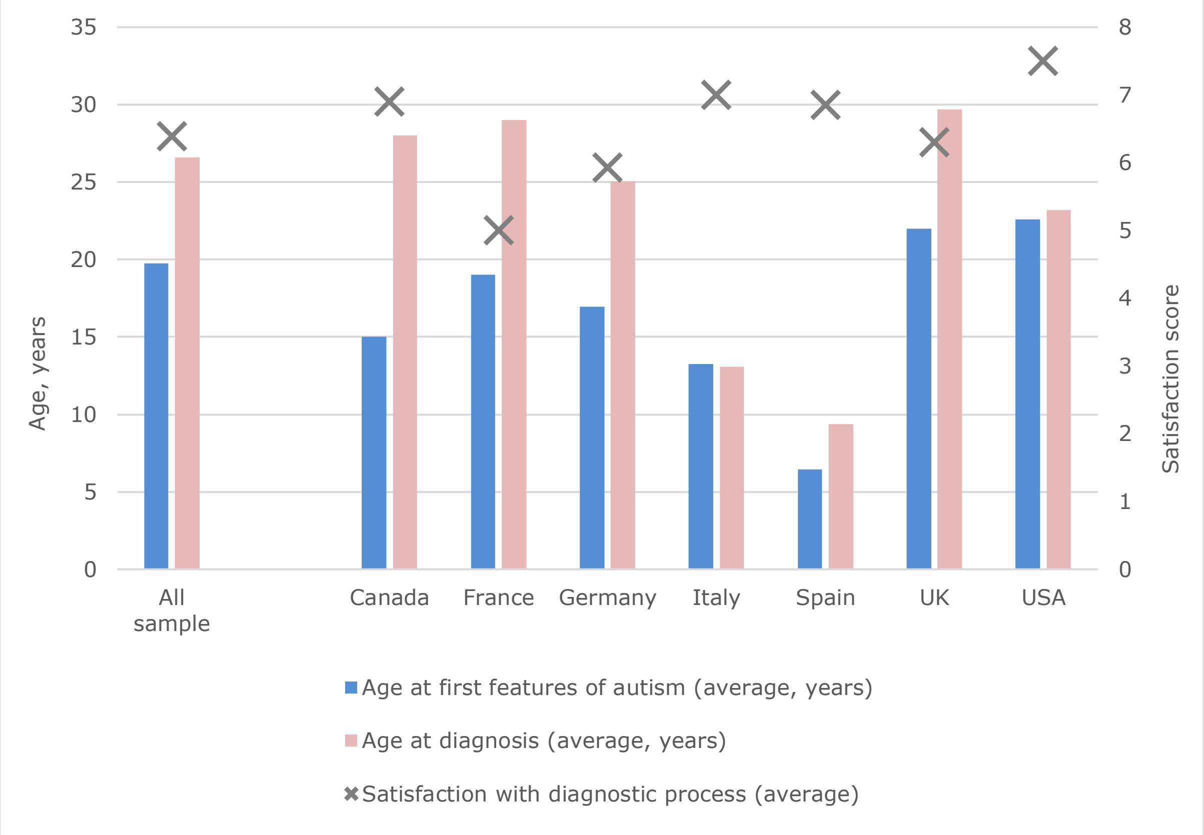

Table 2. Results on the indicators relevant to diagnostic pathways followed across countries.

	Canada (n=7)	France (n=31)	Germany (n=33)	Italy (n=16)	Spain (n=34)	UK (n=280)	USA (n=28)	Total (n=429)
Whom were the first features of autism raised with? n (%)								
• A mental health professional	0%	7 (22.6%)	16 (48.5%)	3 (18.7%)	1 (2.9%)	45 (16%)	8 (28.6%)	80 (18.6%)
• Paediatrician	1 (14.3%)	1 (3.2%)	6 (18.1%)	6 (37.5%)	12 (35.3%)	4 (1.4%)	2 (7.1%)	32 (7.5%)
• Specialist	1 (14.3%)	7 (22.6%)	2 (6%)	0%	1 (2.9%)	26 (9.3%)	2 (7.1%)	39 (9%)
• Teacher	1 (14.3%)	1 (3%)	1 (3%)	2 (12.5%)	9 (26.4%)	20 (7.1%)	3 (10.7%)	37 (8.6%)
• Health visitor/public health nurse/child health nurse	0%	1 (3.2%)	0%	1 (6.2%)	0%	27 (9.6%)	0%	29 (6.8%)
• GP/family doctor/generalist	1 (14.3%)	5 (16.1%)	0%	1 (6.2%)	2 (5.8%)	103 (36.8%)	8 (28.6%)	120 (28%)
• Social worker	1 (14.3%)	0%	0%	0%	0%	1 (0.3%)	0%	2 (0.5%)
• Other	2 (28.6%)	9 (29%)	8 (24.2%)	3 (18.7%)	9 (26.4%)	54 (19.3%)	5 (17.8%)	90 (21%)
Who made your autism diagnosis? * n (%)								
• Educational psychologist	0%	0%	5 (15.1%)	2 (12.5%)	9 (26.4%)	15 (5.3%)	5 (17.8%)	36 (8.4%)
• Neurologist	0%	3 (9.7%)	0%	4 (25%)	9 (26.4%)	5 (1.8%)	4 (14.2%)	25 (5.8%)
• Psychologist	4 (57.1%)	12	11 (33.3%)	8 (50%)	18 (52.9%)	113 (40.3%)	17	183 (42.6%)
• Psychiatrist	2 (28.6%)	22	13 (39.4%)	4 (22%)	8 (23.5%)	60 (21.4%)	4 (14.2%)	113 (26.3%)
• Multi-disciplinary team	0%	5 (16.1%)	10 (30.3%)	2 (12.5%)	6 (17.6%)	79 (28.2%)	1 (3.5%)	103 (24%)
• GP/family doctor/generalist	1 (14.3%)	2 (6.4%)	0%	0%	1 (2.9%)	9 (3.2%)	6 (21.4%)	19 (4.4%)
• Paediatrician	0%	0%	0%	2 (12.5%)	3 (8.8%)	24 (8.5%)	4 (14.2%)	33 (7.7%)
• Private assessment paid for at own expense	1 (14.3%)	5 (16.1%)	3 (9%)	3 (18.7%)	6 (17.6%)	27 (9.6%)	1 (3.5%)	46 (10.7%)
• Other	0%	6 (19.3%)	4 (12.1%)	1 (6.2%)	2 (5.8%)	33 (11.8%)	2 (7.1%)	48 (11.2%)
Who made the initial referral to the healthcare professional that made the diagnosis? n (%)	**Canada (n=7)**	**France (n=31)**	**Germany (n=34)**	**Italy (n=16)**	**Spain (n=35)**	**UK (n=278)**	**USA (n=28)**	**Total (n=429)**
• A mental health professional	1 (14.3%)	6 (19.3%)	3 (8.8%)	0%	1 (2.8%)	38 (13.7%)	1 (3.5%)	50 (11.7%)
• Paediatrician	0%	2 (6.4%)	7 (20.6%)	4 (25%)	19 (54.3%)	5 (1.8%)	2 (7.1%)	39 (9%)
• Teacher	0%	1 (3.3%)	0%	1 (6.2%)	1 (2.8%)	9 (3.2%)	0%	12 (2.8%)
• Health visitor or public/child health nurse	0%	0%	0%	0%	0%	10 (3.6%)	0%	10 (2.3%)
• GP/family doctor/generalist	0%	2 (6.4%)	9 (26.4%)	2 (12.5%)	4 (11.4%)	115 (41.4%)	9 (32.1%)	141 (32.9%)
• Social worker	0%	1 (3.3%)	0%	1 (6.2%)	1 (2.8%)	0%	0%	3 (0.7%)
• Self-referral	2 (28.6%)	9 (29%)	3 (8.8%)	4 (25%)	5 (14.3%)	41 (14.7%)	9 (32.1%)	73 (17%)
• I was not referred	2 (28.6%)	5 (16.1%)	5 (14.7%)	1 (6.2%)	1 (2.8%)	10 (3.6%)	1 (3.5%)	25 (5.8%)
• Multiple referrals by different members on this list	0%	1 (3.3%)	2 (5.9%)	2 (12.5%)	1 (2.8%)	9 (3.2%)	3 (10.7%)	18 (4.2%)
• Other and/or I do not know	2 (28.6%)	4 (12.9%)	5 (14.7%)	1 (6.2%)	2 (5.7%)	41 (14.7%)	3 (10.7%)	58 (13.5%)
Time between first referral and diagnosis, months (SD)	14 (29)	27 (35)	21 (24)	4.5 (4)	10 (14)	24 (50)	34 (122)	23 (60)

Key: *More than one options can apply; percentage calculated across the number of respondents.
Note: n= Number of respondents/responses, SD= Standard Deviation

5. Quality of Life

5.1. Impact of autism on aspects of wellbeing

More than 70% of respondents reported autism has a great or somewhat negative impact on their QoL (Table 3, Appendix Figure 1). Similarly, more than 80% of respondents reported that they feel that autism has a negative impact specifically on their social life either "a great deal" (64%) or at least "somewhat" (20%) (Table 3, Appendix Figure 1). On the contrary, only about a third of respondents reported that autism has a great or somewhat positive impact on their QoL and well-being (Appendix Figure 1). Little fluctuation was observed on QoL outcomes between the different gender categories (Appendix Figure 1). Aspects of well-being that were positively affected by autism included fulfilment from special abilities & creativity (20.6%), greater clarity of mind and focus (15.4%), and receiving or providing help from or to others respectively (15%), among others (Figure 2, Table 3, Table 4) and those negatively impacted included increased anxiety and depression (20.3%), loneliness and difficulty maintaining relationships (18.7%) and difficulty in social interactions and communications (18%) (Figure 2, Table 3, Table 5). Similar to our results, autism research has consistently shown that domains exhibiting the poorest outcomes for autistic people include the ability to have fulfilling relationships with peers and family, to be independent, take part in community activities and pursue employment opportunities (National Collaborating Centre for Mental Health & NICE, 2021). A European study of QoL in adults and children found that, overall, the autism group had lower QoL scores than the comparison group and as demonstrated in our study, depression as a co-occurring condition was a major factor that lowered QoL in autistic adults and children, while sense of achievement was a strong factor determining QoL outcomes in autistic children (Oakley et al., 2021). Country specific studies from the UK and the USA, also corroborate the key domains identified by our study that have a negative impact on QoL outcomes, including a mental health diagnosis (Mason et al., 2018), feeling socially isolated and losing contact with friends or family because of how they responded to their autism (National Autistic Society, 2016).

Additionally, as demonstrated by our results, receiving support, being male and being in a relationship were reported as positive predictors of QoL (Mason et al., 2018). Finally, one percent of autistic individuals in our study reported suicidal behaviour as an aspect of their autism that negatively affects their QoL (Figure 2). Literature has recognized that suicidal behaviour is common among autistic individuals (Autistica, n.d.; Cassidy et al., 2014), although in a much higher prevalence compared to our study, ranging from 14% of autistic children experiencing suicidal thoughts to between 30% and 50% of autistic adults having considered suicide (Autistica, n.d.; Cassidy et al., 2014).

5.2. Impact of autism on health status

On an impact scale from 0 (no effect on ability to carry out daily activities) to 10 (completely affected ability to carry out daily activities), respondents rated the average impact of autism on their ability to carry out daily activities in an average month as 5.6, ranging from 4.5 in Italy to 5.8 in Germany and 5.9 in Spain (Table 1). On a self-rated health scale from 0 (worst health possible) to 100 (best health possible)[3], respondents rated their average physical health as 65 (±25) and average mental health as 54 (±27), although country-specific discrepancies were observed, ranging from as high as 76 (±24) and 75 (±20) respectively in the USA and as low as 53 (±29) and 49 (±25) respectively in France (Table 1).

Additionally, the impact of autism on carrying out daily activities increased with increasing autism severity, ranging from 4.9 for those with no problem communicating verbally, 6.1 for those having some difficulty communicating verbally and 7.4 for those that are completely non-verbal. Similarly, on the self-rated mental health scale, average scores decreased with increasing severity level, ranging from 51 (±33) for completely non-verbal individuals, 53 (±26) for those having some difficulty communicating verbally and 56 (±26) for those with no problem communicating verbally. Nevertheless, self-rated physical health status didn't necessarily and/or significantly worsen with autism severity level; the lowest score was observed for those having some difficulty communicating verbally, followed by completely non-verbal individuals and those with no problem communicating verbally (63 (±25), 66 (±30), and 67 (±23) respectively).

Finally, discrepancies were observed between the self-perceived health and mental health status reported by autistic individuals themselves vs. supporters responding on behalf of autistic individuals, rated as 62 (±25) and 51(±26) vs. 70 (±24) and 59 (±26) respectively.

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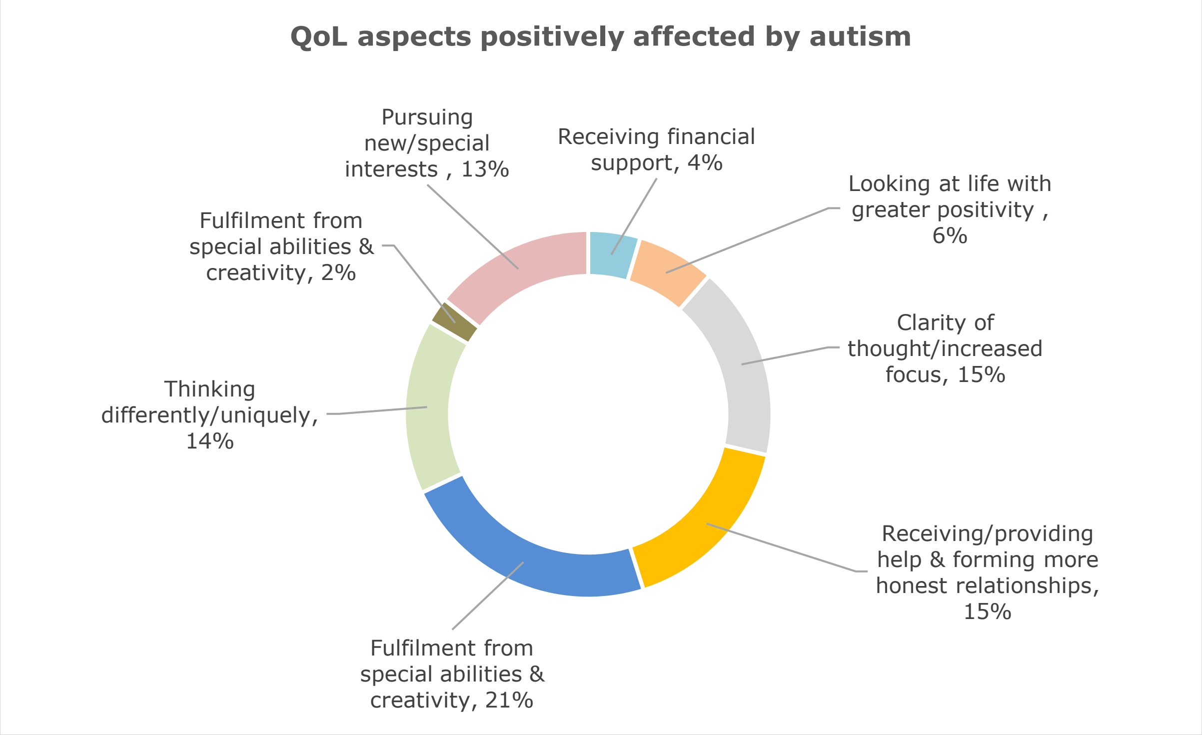
[3] *This measurement is based on the EuroQol Five Domain Health Questionnaire (EQ-5D) Visual Analog Scale, which has been used elsewhere to measure the impact of autism on autistic children's' health status and quality of life (ten Hoopen et al., 2020).*

Key findings on quality of life outcomes

- Autism had a primarily negative impact on QoL and specifically on social life for more than 70% and 80% of respondents, respectively. Key aspects negatively affected were increased anxiety and depression, loneliness and difficulty maintaining relationships and difficulty in social interactions/communications.
- Autism had either a great or somewhat positive impact on QoL for 29% of respondents. Key aspects of QoL positively affected were fulfilment from special abilities & creativity and greater clarity of mind/focus.
- On a scale from 0 (no impact) to 10 (complete impact on daily activities), average impact of autism on ability to carry out daily activities in an average month was 5.6.
- On a health scale from 0 (worst state possible) to 100 (best state possible), respondents' average physical and mental health status was 65 (±25) and 54 (±27) respectively.

Figure 2. Aspects of autistic individuals' QoL and well-being affected positively and negatively by autism.



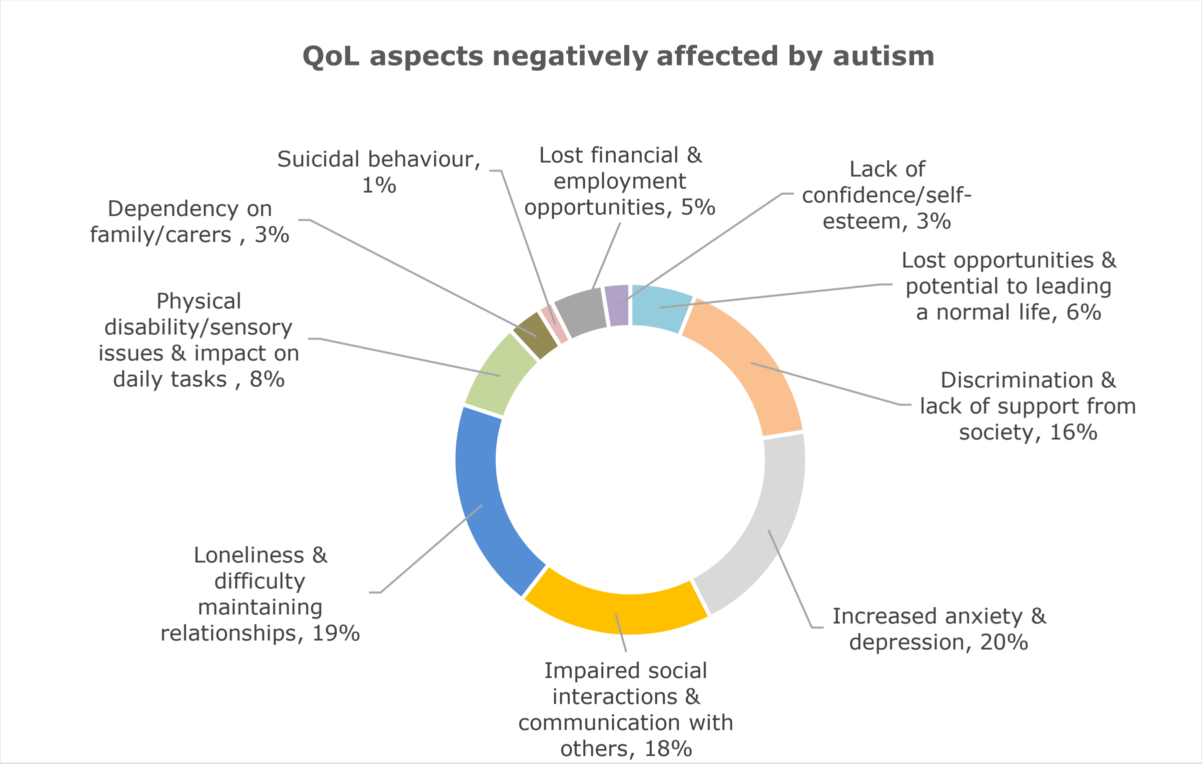


Table 3. Key aspects of wellbeing that were positively and negatively impacted by autism across countries, n (%).

	Canada (n=4)	France (n=10)	Germany (n=16)	Italy (n=6)	Spain (n=7)	UK (n=109)	USA (n=23)	Total (n=194)
Aspects affected positively								
• Fulfilment from special abilities and creativity	1 (25%)	3 (30%)	4 (25%)	0%	0%	29 (26.6%)	3 (13%)	40 (20.6%)
• Receiving or providing help and forming more honest relationships	0%	0%	3 (18.7%)	3 (50%)	4 (57.1%)	13 (11.9%)	6 (26%)	29 (15%)
• Clarity of thought and increased focus	2 (50%)	0%	3 (18.7%)	0%	1 (14.3%)	21 (19.2%)	3 (13%)	30 (15.4%)
• Thinking differently/uniquely	0%	2 (20%)	1 (6.2%)	1 (16.7%)	1 (14.3%)	19 (17.4%)	2 (8.7%)	26 (13.4%)
• Pursuing new or special interests	0%	3 (30%)	1 (6.2%)	0%	0%	17 (15.6%)	4 (17.4%)	25 (12.9%)
	Canada (n=6)	**France (n=34)**	**Germany (n=23)**	**Italy (n=15)**	**Spain (n=23)**	**UK (n=249)**	**USA (n=19)**	**Total (n=369)**
Aspects affected negatively								
• Increased anxiety and depression	1 (16.7%)	3 (8.8%)	5 (21.7%)	1 (6.7%)	0%	65 (26.1%)	0%	75 (20.3%)
• Loneliness and difficulty maintaining relationships	2 (33.3%)	13 (38.2%)	1 (4.3%)	1 (6.7%)	3 (13%)	41 (16.4%)	8 (42%)	69 (18.7%)
• Impaired social interactions and communication with others	2 (33.3%)	3 (8.8%)	3 (13%)	3 (20%)	3 (13%)	48 (19.3%)	5 (26.3%)	67 (18.1%)
• Discrimination and lack of support from society	0%	5 (14.7%)	4 (17.4%)	3 (20%)	3 (13%)	39 (15.6%)	4 (21%)	58 (15.7%)

Key: Aspects listed here reflect only the top categories among all aspects affected; respective percentages reflect the proportion out of all categories of aspects reported among all respondents per country

Note: n= Number of respondents/responses

Table 4. Examples of respondents’ perspectives on how autism has positively impacted their wellbeing.

Country	Fulfilment from special abilities and creativity	Receiving help and forming more honest relationships	Clarity of thought and increased focus	Thinking differently/ uniquely	Pursuing new and special interests
Canada	• *“Superior intelligence has certainly been nice. I grasp new concepts and learn new skills extremely quickly. I've never really had any doubt about my abilities in that regard because everything has always been easy.”*		• *“I can put myself first and focus on what I want to do (vs appeasing others, being worried about fitting in).”*		
France	• *“I am full of ideas and too imaginative.”* • *“The ability to become fully absorbed in an interest or task.”*			• *“I have a way of perceiving, conceiving and feeling the world that is unique to me and that I love.”*	• *“My interests reinstate my intelligence.”*
Germany	• *“I notice details early on that often become important later and that nobody thinks about.”* • *“I appear very charismatic to other people, easily attracting attention.”*	• *“Made great, honest friendships because of autism.”*	• *“Because of my systematic way of doing things, I consider different variables before taking decisions and therefore I regret very few of them.”* *“My interests reinstate my intelligence.”*	• *“I get along very well on my own and can do almost everything I plan to do on my own.”*	• *“I have a lot of skills and interests and a broad artistic portfolio. I have been able to acquire a lot of special interests and can also teach this in a good and entertaining way. In this respect I have been able to turn need into virtue.”*
Italy		• *“I am a very sensible person who loves helping others.”*		• *“Originality in completing projects differently.”*	
Spain		• *“Received a lot of help.”*		• *“Being different.”*	
UK	• *“I can take on board a lot of information and store it away. I become especially fixated on topics and have learnt new skills on my own which have benefited me in obtaining employment.”* • *“I have skills others don't - a really good memory and an eye for detail that helps me in my job a lot.”*	• *“Since coming to terms with being autistic, I have found my tribe. I have found my voice and my vocation. it is at the center of what I do. My goal is for the next generation to not have to go through what I did.”* • *“I am honest with myself and others which fosters strong, genuine friendships”*	• *“Focused, rational and logical approach to issues is a great advantage in school and in life”.* • *“Allows me to think for myself and not be hampered by various social and cognitive conventions.”*	• *“It allows me to think differently, I have different ideas that others will never think off.”* • *“It allows me to see the world from a different perspective.”*	• *“The autistic special interests I cultivated somewhat annoyingly as a child have grown into hobbies which bring me deep joy and fulfilment.”* • *“I have very strong interests which can keep me occupied for hours. I feel lucky to be wired up this way.”*
USA	• *“I have been able to succeed in my chosen fields because of autism. I have a very good memory and read well and a lot.”*	• *“It has had an overall positive impact on my current friendships. I tend to befriend neurodiverse people; we understand each other's idiosyncrasies well.”*	• *“Autism has given me gifts that let me laser focus on tasks and chores.”*	• *“I believe I see things in an incredibly interesting and individual light.”*	• *“Special interests are so fun and have led to me developing all sorts of neat hobbies and learning cool things!” “I get along very well on my own and can do almost everything I plan to do on my own.”*

Table 5. Examples of respondents' perspectives on how autism has negatively impacted their wellbeing.

Country	Increased Stress and anxiety	Loneliness and difficulty maintaining relationships	Impaired social interactions and communication with others	Discrimination and lack of support from society
Canada		• *"Close interpersonal relationships aren't really an option for me. I've yet to meet someone I can truly be myself with. As a result, every relationship I have is a net negative experience."*	• *"Uncomfortable with socializing; impacts networking for personal, romantic, and professional areas of life. Been told I can spend too much time alone."*	• *"I was put aside by my family because of my difference."*
France	• *"Stress, meltdown/shutdown"*	• *"No/very few friends, few fulfilling relationships, the feeling of being alone all the time."*	• *"Communication with others is difficult."*	
Germany	• *"High stress in everyday life from noise and human contact."*	• *"Formative negative experiences in school, failed social contacts, excessive demands on neurotypical thinking in wide areas of society."*	• *"10 years in voluntary isolation, with permanent suicidal / constant feeling of being overwhelmed."*	• *"Bullying and exclusion and not being able to understand social interaction or social situations or not being able to express oneself properly and therefore not being able to stand up for one's rights or defend oneself properly."*
Italy	• *"I suffer from panic attacks."*	• *"Social life with peers non-existent, inability to joke and make irony with peers, interests that cannot be shared with peers because they are typical of a younger age."*	• *"I have minimal social relationships. I rarely get invited by my two childhood friends or by my family. I avoid contact with strangers so as not to expose myself to mistreatment and mortification."*	• *"I am regarded as a limitation, an obstacle."*
Spain		• *"Limits social life greatly."*	• *"Social isolation. No friends and no job."*	• *"Society is not prepared at the level of consciousness or resources."*
UK	• *"I experience a lot of anxiety in many aspects of life and have gone through periods of depression".* • *"Severe anxiety and depression due to sensory overload, social anxiety, social isolation, bullying."*	• *"Inability to make/maintain relationships, so I feel lonely most of the time."* • *"I'm lonely and miserable. I don't have any friends - I can't seem to maintain any friendships or relationships."*	• *"I find social interactions difficult to understand, predict and manage."* • *"Socializing is very hard. I don't like leaving the house on my own or going to shops alone. I get overwhelmed when routines change or by certain lights/sounds/touch/smells."* • *"Very difficult to be around people and communicate with them."*	• *"World is not built for neurodivergent people; constantly expected to mask, can't obtain employment, can't get disability benefits, no real support available."*
USA		• *"Many kinds of relationships I struggle with, especially passing acquaintances and romantic interests. I don't read social cues well, so with people who don't already know/like me, that can be a challenge."*	• *"The lack of ability to understand the nuances of socializing has caused my social life in the past to be sadly lacking."*	• *"Autism hasn't impacted my life poorly. But society's treatment of autistic people has. Bullying being the main one when I was a kid. From both other kids and from teachers and authority figures."*

6. Direct healthcare costs

6.1. Out-of-pocket expenses

Cumulative, average, monthly out-of-pocket expenses for autistic individuals amounted to €1,368 (±363) across all countries (Figure 3), ranging from a cumulative monthly average of €729 (±32) for individuals under 18 to €1,351 (±165) for individuals aged 18 and over. Out-of-pocket costs are predominantly generated by expenses on childcare (€133; 10% of all monthly costs), support worker or personal assistant (€115; 8% of all monthly costs), privately funded therapies (€109; 8% of all monthly costs) and various, "other"[4] expenses (€641; 47% of all monthly costs) (Figure 4). A significant inter-country variation was observed in the total, monthly out-of-pocket expenses reported by respondents, ranging from as little as €337 (±83) in Germany up to €2,470 (±705) and €2,877 (±801) in Canada and USA respectively (Figure 3).

67% (n=290) of respondents across all countries, reported receiving no state or health insurance funded financial support for their autism related costs (e.g., disability allowance, personal independence payment), ranging from 86% of respondents in Canada, and 83% of respondents in both Germany and USA, to 64% and 62% of respondents in Spain and the UK, respectively. Only 33% (n=144) of respondents reported that they have received state or health insurance funded financial support due to autism, including 38% (n=106) of respondents in the UK (e.g., Disability Living Allowance (DLA), Personal Independence Payment (PIP), Employment and Support Allowance (ESA)), 36% (n=13) in Spain (e.g., dependency help, disability benefit, non-contributory pension, deduction for disability and large family from the state treasury), 29% (n=5) in Italy (e.g., disability benefit, accompaniment allowance, disability pension), 25% (n=8) in France (e.g., Allocation aux Adultes Handicapés (AAH)), 17% (n=5) in the US (e.g., Supplemental Security Income (SSI)), 17% (n=6) in Germany (e.g., care allowance, home help) and 14% (n=1) in Canada (e.g., Ontario Disability Support Program (ODSP)).

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[4] *A variety of miscellaneous out-of-pocket expenses were reported such as trying new interventions like weighted blankets or headphones, software to help with learning, items to help with sensory issues, home-education, preparing fresh homemade meals/special food and sensory diet items, monthly subscriptions to magazines/clubs to maintain special interests, materials needed for education and wellbeing (e.g., reading slope for home and school, pen holders, books on special interest topics to help learn to read, activity books to improve pen control), books about autism to help parents understand autistic children's needs, chewy necklace for sensory needs, private counselling and one-off diagnostic assessment fees, special lightning and furniture, mobility aids (e.g., wheelchairs), gym and private training.*

Our findings are comparable to some of the country-specific figures reported in Canada, Germany, Italy, the UK and the USA. For example, in Germany we found that the mean annual costs per individual are about €4,044 (±996) which is consistent with figures reported in the literature suggesting that average annual costs per person were €3,287, ranging between €4,864 and €2,936 for females and males respectively, and the largest cost components included psychiatric inpatient care (20%), pharmacotherapy (11%), and Occupational Therapy (OT) (11%) (Höfer et al., 2021).

In Canada, average annual costs for autistic children between two to five years have been estimated to range from €3,800 to €57,500 for children without vs. with intervention respectively, while between ages five and eighteen the estimated annual costs (per individual) can range from €4,700 to €15,100 and up to €27,400 for independent[5], semi-dependent and highly dependent individuals respectively (Avis & Prado, 2012).[6]

In Italy, in a cohort of children with special health care needs, it was reported that families of autistic children spent about €200 (±133) monthly on complementary and alternative medicines (Taneja, Sharma, Bhatt, & Kumar Bhutani, 2017) which is consistent with our figure of about €150 spent monthly on complementary and other medications related to autism symptoms.

In the UK, estimated average out-of-pocket expenses per month were €564 (±154), translating to €6,768 (±1,848) per autistic individual per year, with privately funded therapies and legal fees related to for example, education provision, being among the top drivers of costs. This figure is consistent with a study of 19 autistic young adults, which reported an average annual cost for community support of €7,154 (Järbrink, McCrone, Fombonne, Zandén, & Knapp, 2007). Nevertheless, higher figures have been reported elsewhere varying from €12,780 (£11,029) among a childhood autism group to €10,390 (£8,968) among a broader autism group, over a 6-month period, with the costs of education services accounting for almost 90% of total costs in both groups (Barrett et al., 2015). Other sources have

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[5] *The study classified dependency levels based on the following definitions; "Independent"= Mainstream classroom education; independent functioning; earn average Canadian high school graduate income as adults, "Semi-dependent"= Special education; respite services; 50% live independently as adults; 50% live in residential facilities; participate in day programs; earn assisted employment income as adults, "Highly dependent"= Intensive special education; respite services; 100% live in residential facilities as adults; participate in day programs; earn assisted employment income as adults (Motiwala et al., 2006).*

[6] *In our study, subgroup analysis per autism severity level (i.e., based on ability of verbal communication) did not demonstrate increased costs with increasing severity. Individuals who were completely non-verbal had the lowest mean, monthly costs (€817 (±105)) compared to those with some or no problem communicating verbally (€2406 (±348)) and €1045 (±131) respectively). However, this discrepancy could be largely attributed to the significantly smaller cohort of completely non-verbal individuals compared to the other two groups.*

estimated that about 50% to 60% of costs are accounted for by autism support services provided (Prado, 2012) and special education, including early intervention services (Byford et al., 2015).

Among our study countries, USA exhibited the highest cumulative, mean annual out-of-pocket costs per person amounting to €34,524 (±9,612) per year with a significant proportion arising from medication for autism symptoms, privately funded therapies, medication costs and optician, dentist or dietitian costs (Figure 3). Similarly, in 2007, it was estimated that costs arising from behavioural therapies only were €26,169 ($32,000) during the 5-year age group, while physician and dental costs, prescription fees, complementary and alternative therapies, and hospital and emergency services were also relatively high but steadily declined with age (Ganz, 2007).

Key findings on direct healthcare costs

- Average monthly out-of-pocket expenses for autistic individuals were €1,368 (±363), ranging from €337 (±83) in Germany to €2,877 (±801) in the USA, and from €729 (±32) for individuals under 18 to €1,351 (±165) for individuals aged 18 and over.
- Direct healthcare costs were predominantly generated by expenses on childcare (10% of all monthly costs), support worker or personal assistant (8%), privately funded therapy (8%) and various "other" categories of expenses reported (47%), such as special equipment for education and dietary needs, one off diagnostic fees and mobility aids.
- 67% of autistic individuals reported that they have received no state or health insurance funded financial support for their autism related costs.

Figure 3. Average cumulative monthly costs per autistic person across all sample (€, 2021) and per country (€, 2021).

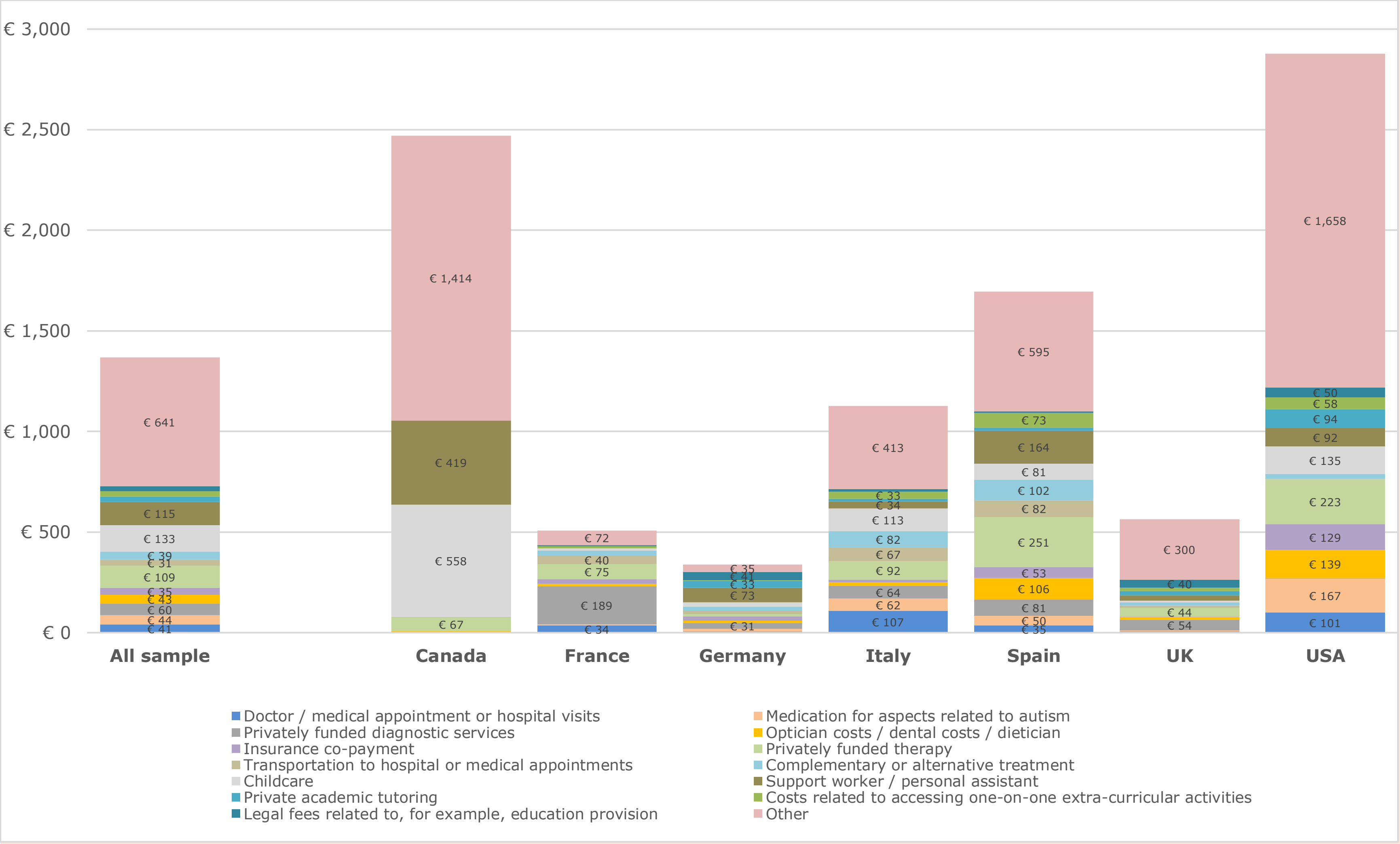
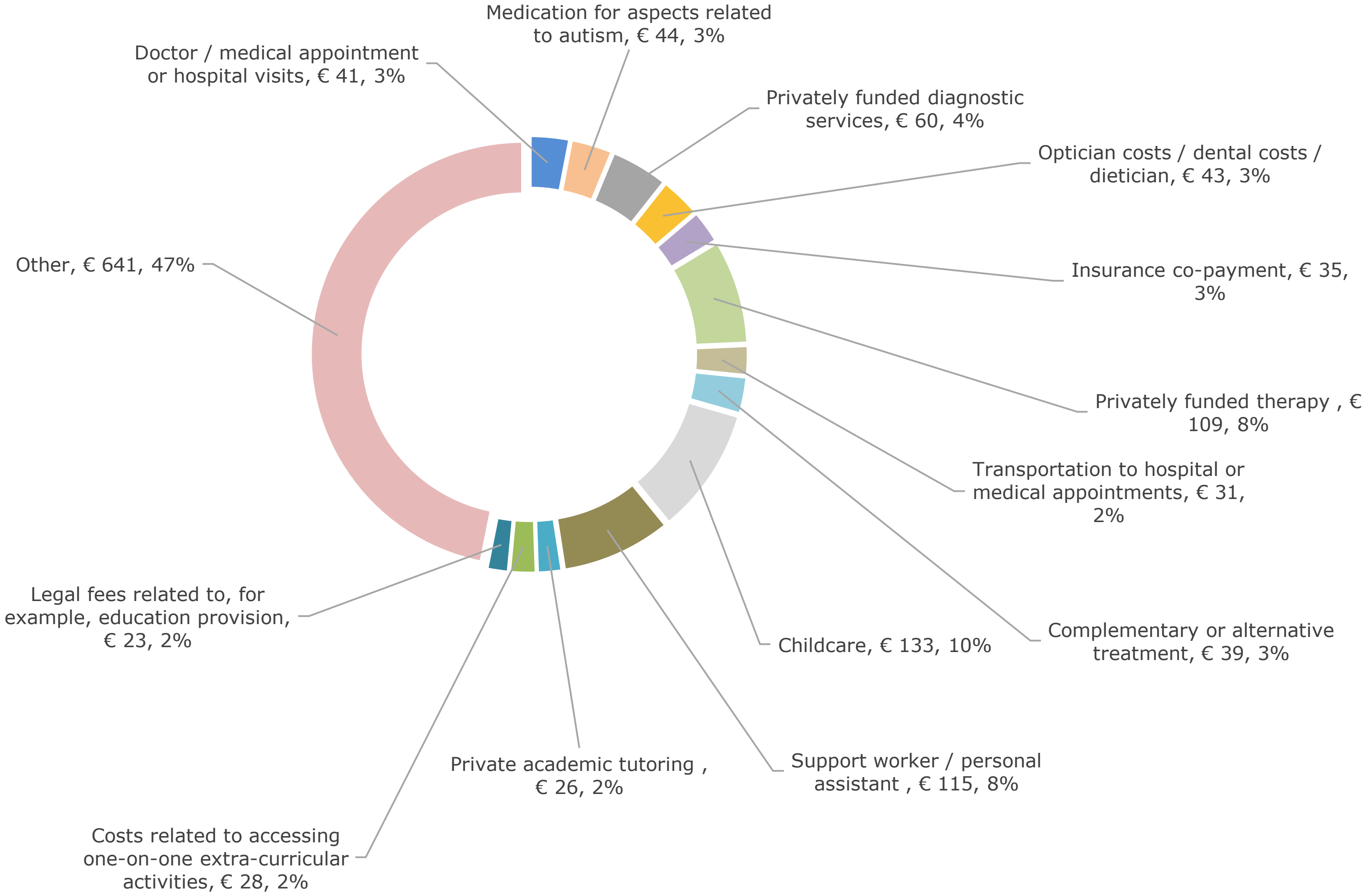


Figure 4. Average monthly out-of-pocket expenses across different categories of expenses and across all sample.



7. Support and therapy after diagnosis

7.1. Visits to healthcare professionals

In terms of care received after diagnosis, it was demonstrated that overall, autistic individuals most commonly visit a psychologist, at an average of seven visits per year, followed by speech therapist, occupational therapist, and a social worker, all at an average of four visits per year. Nevertheless, significant discrepancies were observed across the country-specific numbers reported, ranging for example from an average of one psychologist visit per year in Canada, to 29 visits in Spain, and an average of one occupational therapist visit per year in the UK and France to 47 visits per year in Spain (Appendix Figure 2). Our findings are consistent with results from Canada indicating that autistic young adults are more likely to have at least one visit to the family physician, paediatrician, and psychiatrist (Weiss et al., 2018). More precisely, the estimated mean number of annual psychiatric medical visits in Canada is 7.5 one year after autism diagnosis, falling to two visits five years after autism diagnosis (Perreault, Croteau, Mottron, Tarride, & Dorais, 2015). Similarly, in the US, eight annual physician visits have been reported for autistic children (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006). Additionally, in the USA a significant number of OT visits has been observed (Vohra et al., 2017), which is consistent with our finding of nine annual occupational therapist visits. Finally, our UK participants reported the lowest overall number of visits to autism related healthcare professionals compared to the total number of visits reported in the other study countries. High rates of missed appointments among autistic individuals in the UK have been reported elsewhere (BMA, 2019). Delayed or forgone care among autistic individuals can be in part due to autistic individuals' need to adhere to strict routines and the potential sensory overload medical appointments present. Literature suggests that sensory sensitivities, such as the experience of the waiting and examination rooms and/or the examination itself, being a major barrier to accessing care (Mason et al., 2019).

7.2. Medication utilisation

Most autistic individuals in our study did not take any medication specifically related to health aspects associated with their autism (41%, n=226), and of those who took some medication, antidepressants (e.g., Fluoxetine, Citalopram/Escitalopram, Sertraline) (19%, n=103) were the most used category of medications across countries. Nevertheless, country-specific discrepancies were observed such as in Spain and France where the predominant category of medications used was antipsychotic drugs (e.g., Aripiprazole, Olanzapine, Quetiapine) (24%, n=12 and 15%, n=7 respectively) (Figure 5). Studies in the USA confirm that psychotropic drug use is common in autistic individuals (Houghton et al., 2017; Khanna, Jariwala, & West-Strum, 2013a) and comparable to our findings, the highest rates of utilization for autistic children over 8 were for antidepressants (32%), stimulants (27%), and antipsychotics (24%)(Shimabukuro, Grosse, & Rice, 2008). Higher utilization rates of drugs for mental health related aspects of autism have been reported in Canada, starting from about 49% of individuals shortly after diagnosis of autism and increasing to 53% five years after diagnosis (Perreault et al., 2015).

7.3. Interventional therapies

Most autistic individuals in our study have not received any interventional therapies (45%, n=200). Of those who have received such therapies, Cognitive Behavioural Therapy (CBT) (24%, n=107) was the most commonly received intervention across countries, although country-specific discrepancies were observed in Spain, Germany and the USA where the predominant category of interventional therapy received was Social Skills Groups (SSGs) (30%; n=17, 22%; n=7 and 27%; n=12 respectively) (Figure 6). Among individuals who received at least one interventional therapy, Verbal Behaviour Therapy (VBT) and Relationship Development Intervention (RDI) were the most frequently rated as "very beneficial" (50%; n=8 and 45%; n=9 respectively), followed by SSG and CBT (38%; n=26 and 34%; n=36 of individuals who used these interventions respectively). Nevertheless, CBT and SSGs were also the top therapies rated as making "no difference" (15%; n=16 and 10%; n=7 of respondents respectively), while CBT was also among the few therapies rated as "very harmful" or "somewhat harmful" by 3% (n=3) and 6% (n=6) respectively, of individuals who used CBT (Appendix Figure 3). On average, individuals who used (and rated) the above interventions reported that they have roughly received 122, 76, 65 and 55 sessions of VBT, RDI, CBT and SSG respectively. Average waiting times between being referred for the therapy and receiving it ranged from 2 months for RDI, 8 months for CBT and SSG and up to 10 months for VBT.

Literature suggests that different diagnostic and intervention approaches are used in North America and Europe. More precisely, Applied Behaviour Analysis (ABA) therapy is the standard intervention in the USA and Canada, but adoption of this method has been slower in Europe (Keenan et al., 2015), most likely due to controversies surrounding its practice within the autism community. ABA is often criticised for focusing on training autistic individuals to behave as non-autistic, rather than acknowledging the value of their behavioural and cognitive diversity. As such, ABA is not always supported in European countries, while professional ABA training is not available in most European countries (Keenan et al., 2015).

In our study, this was shown in the UK, France, and Spain where only 2%, 3% and 9% of individuals respectively received ABA. Specifically in Spain, efforts to encourage adoption of ABA have been made (Keenan et al., 2015), although our findings suggest uptake of this intervention still remains low compared to other interventions such as SSGs and CBT.

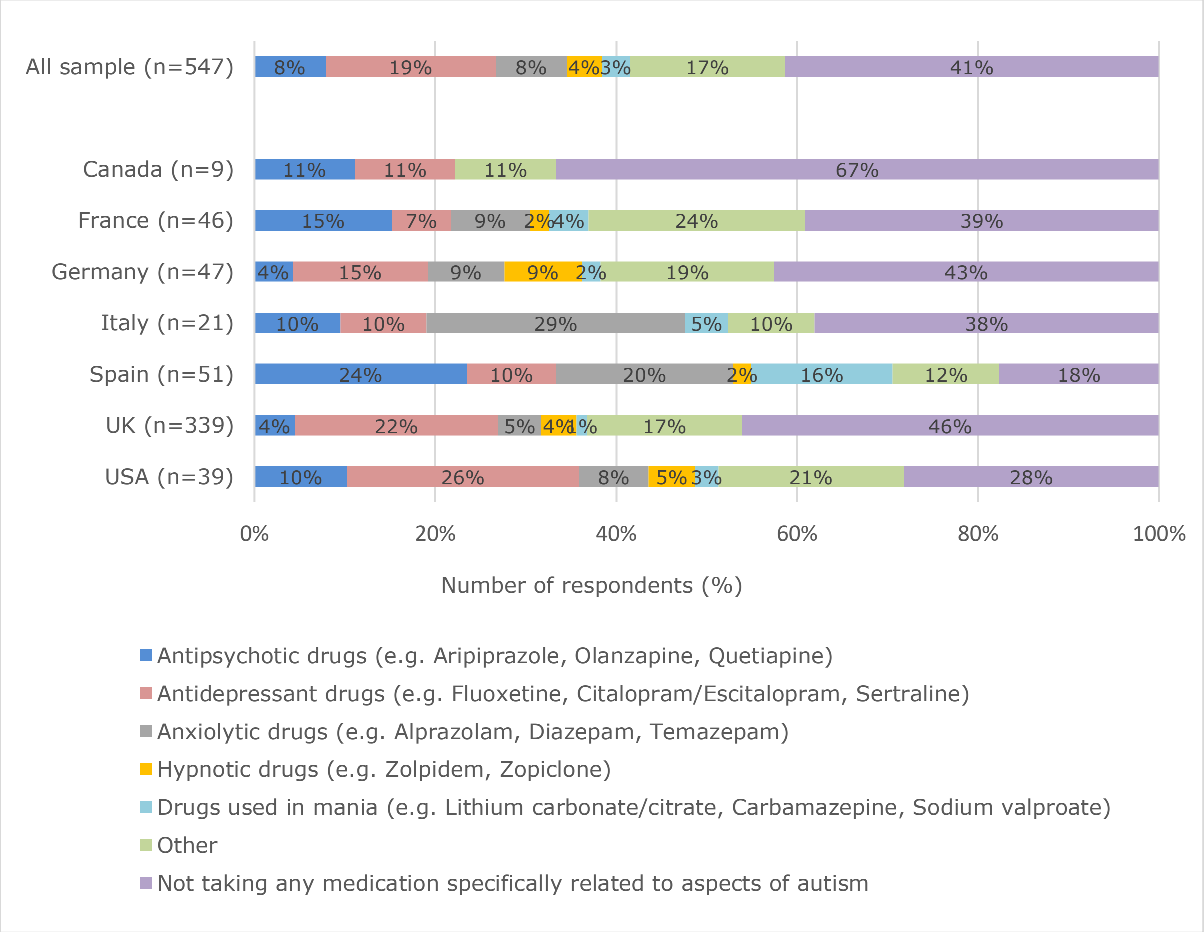
7.4. Input from social services

Only 18% (n=75) of autistic individuals reported receiving input from social services, but more than 40% reported that they receive (39%, n=166) or have received in the past (6%, n=26) government-funded financial support (benefits) because of their autism diagnosis. For those who have not received financial support, key reasons included "not applying due to the belief of being ineligible" (33%) and "haven't applied at all" (33%) (Table 6). Little fluctuation was observed across countries in terms of support received by autistic individuals, with Spain typically exhibiting higher than average numbers of autistic individuals that received social and financial support (27% and 47% of respondents respectively) (Table 6). Our results are consistent with country specific literature from Italy and the USA. In Italy support and services are provided free of charge to children with disabilities and their families, but their implementation and level of utilisation depends on regional regulations, while specifically for autism related services, due to the lack of centralised autism resource or diagnostic centres, these services come with long waiting lists (Keenan et al., 2015). This is in part confirmed by our results which demonstrated that more than 80% of respondents in Italy reported no input from social services. Similarly, our study shows that only about 20% and 30% of autistic individuals receive social services and financial support, respectively, in the USA. Literature suggests that only a few autistic adults in the USA receive autism-specific assistance, while systems, such as service agencies and college disability support offices are seldom of use for autistic individuals because they are not designed to meet their needs (C. Anderson, Lupfer, & Shattuck, 2018). Finally, some discrepancies were observed between our findings in Canada and Germany and the respective literature. For example, in Canada, more than half of autistic individuals with a low income threshold have been reported to receive disability related financial support (Autism Nova Scotia, 2015). Nevertheless, in our study only 37% of individuals in Canada reported receiving financial input. In Germany, while the care of autistic individuals lies largely with the state health and social care sectors (Keenan et al., 2015), only about 20% of autistic individuals from Germany in our study reported receiving social care support.

Key findings on support & therapy after diagnosis

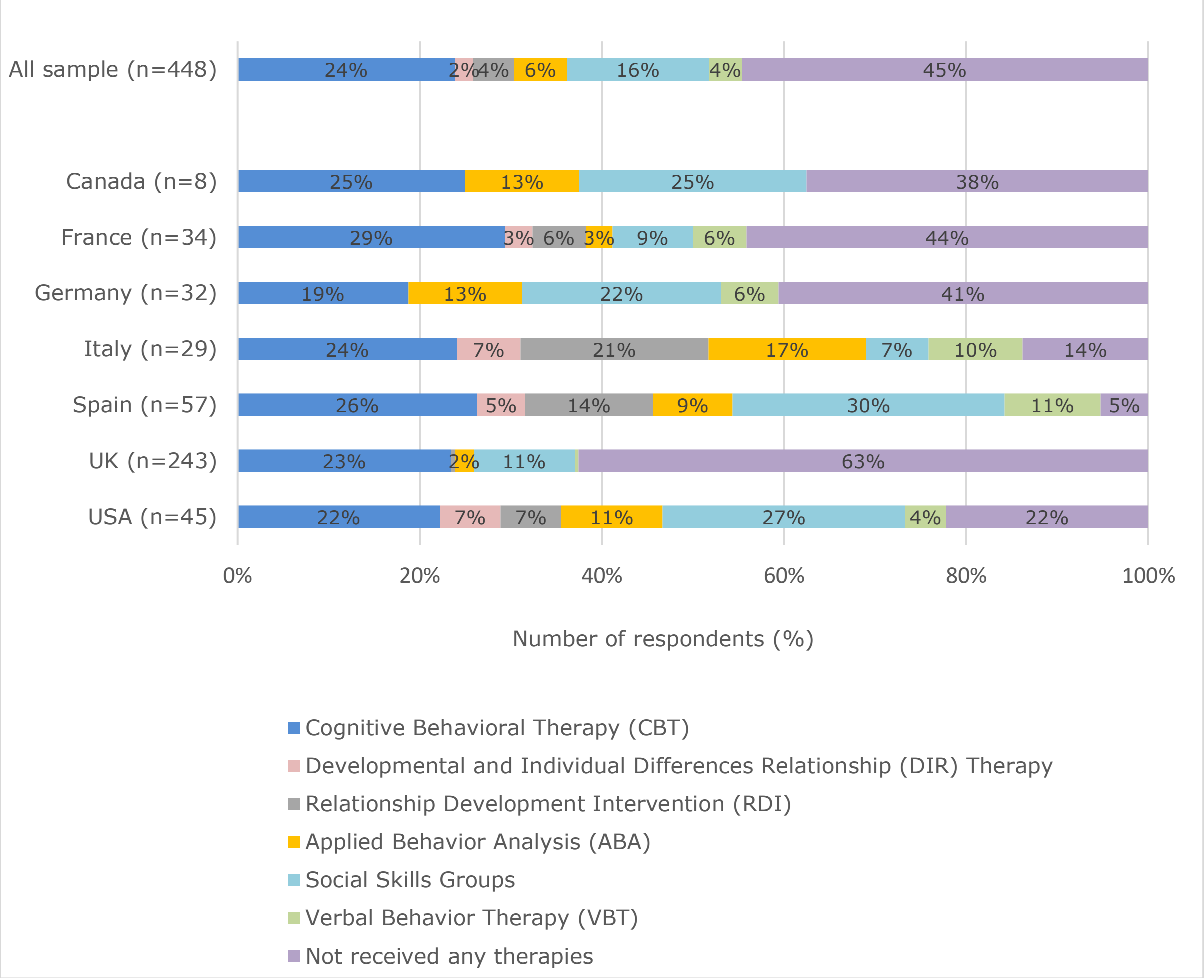
- On average, autistic individuals visit a psychologist seven times per year, followed by four visits per year at speech and occupational therapists and social workers.
- 41% of autistic individuals do not take any medication specifically for autism but of those who do, antidepressants were most used.
- 45% of autistic individuals do not receive/have not received interventional therapies and of those who did, CBT was the most commonly received therapy.
- VBT and RDI were the top interventions rated as "very beneficial", followed by SSG and CBT, but CBT and SSG were also the top interventions rated as making "no difference".
- Only 18% of autistic individuals reported receiving input from social services, but more than 40% receive or have received in the past government funded financial support.

Figure 5. Use of medication specific to health aspects associated with autism, across countries.



Note: *"Other" medication categories reported included Proton Pump Inhibitors for GI problems (e.g., reflux), melatonin and other complementary sleeping aids, herbal remedies, and vitamin supplements; More than one option can apply for each respondent, therefore sample size corresponds to the total number of options chosen.*

Figure 6. Behavioural/psychological therapies or interventions received as part of autistic individuals' autism care program, overall and across countries.



Note: *More than one option can apply for each respondent, therefore sample size corresponds to the total number of options chosen.*

Table 6. **Social and financial support received by autistic individuals, overall and across countries.**

	Canada (n=8)	**France (n=30)**	**Germany (n=34)**	**Italy (n=17)**	**Spain (n=37)**	**UK (n=272)**	**USA (n=28)**	**Total (n=426)**
Do you receive any kind of input from social services, n (%)								
• Yes	2 (25%)	7 (23.3%)	7 (20.6%)	2 (11.7%)	10 (27%)	41 (15%)	6 (21.4%)	75 (17.6%)
• No	6 (75%)	19 (63.3%)	26 (76.4%)	14 (82.3%)	21 (56.7%)	227 (83.4%)	20 (71.4%)	333 (78.2%)
• I don’t know	0%	4 (13.3%)	1 (2.9%)	1 (5.9%)	6 (16.2%)	4 (1.5%)	2 (7.1%)	18 (4.2%)
	Canada (n=8)	**France (n=30)**	**Germany (n=34)**	**Italy (n=17)**	**Spain (n=36)**	**UK (n=271)**	**USA (n=28)**	**Total (n=424)**
Do you receive any government-funded financial support (benefits) as a result of your autism diagnosis? n (%)								
• Yes	3 (37.5%)	11 (36.7%)	10 (30.3%)	3 (17.6%)	17 (47.2%)	114 (42%)	8 (28.5%)	166 (39.1%)
• Not currently but have in the past	0%	0%	2 (6%)	3 (17.6%)	4 (11.1%)	13 (4.8%)	4 (14.3%)	26 (6.1%)
• No, have never received	5 (62.5%)	17 (56.7%)	21 (61.7%)	10 (58.8%)	11 (30.5%)	141(52%)	15 (53.6%)	220 (51.9%)
• I do not know	0%	2 (6.6%)	1 (3%)	1 (5.9%)	4 (11.1%)	3 (1.1%)	1 (3.5%)	12 (2.8%)
	Canada (n=5)	**France (n=17)**	**Germany (n=26)**	**Italy (n=15)**	**Spain (n=17)**	**UK (n=162)**	**USA (n=18)**	**Total (n=260)**
Why do you not receive financial assistance? n (%)								
• I have not applied	2 (40%)	7 (41.2%)	11 (64.7%)	6 (40%)	3 (17.6%)	47 (29%)	9 (50%)	85 (32.7%)
• I applied but did not qualify	0%	0%	0%	0%	4 (23.5%)	19 (11.7%)	0%	23 (8.8%)
• I have not applied because I believe I would be found	2 (40%)	6 (35.3%)	6 (35.3%)	2 (13.3%)	2 (11.8%)	61 (37.6%)	7 (38.9%)	86 (33%)
• I applied and did not qualify, but I am appealing the decision	0%	1 (5.9%)	1 (5.9%)	1 (6.7%)	0%	4 (2.5%)	0%	7 (2.7%)
• I am in the process of applying	1 (20%)	3 (17.6%)	5 (29.4%)	3 (20%)	3 (17.6%)	17 (10.5%)	1 (5.5%)	33 (12.7%)
• Tried or started to apply but the process was too difficult and/or time consuming	0%	0%	3 (17.6%)	2 (13.3%)	2 (11.8%)	13 (8%)	0%	20 (7.7%)
• It is not available in my country	0%	0%	0%	1 (6.7%)	3 (17.6%)	1 (0.6%)	1 (5.5%)	6 (2.3%)

Note: n= Number of respondents/responses

8. Education

In terms of education, 31% (n=352) of respondents were educated through primary school, 29% (n=328) through secondary school, 16% (n=186) through university and 9% (n=104) through postgraduate education. Additionally, 6% (n=66) completed vocational training, 6% (n=68) specialist education[7], and 3% (n=37) home-schooling (Appendix Table 1).

In terms of autism's impact on educational aspects, a notable difference was observed on the academic work/ performance impact reported between respondents with different levels of autism severity (based on verbal communication ability). On a scale from -5 (extremely negative impact) to 5 (extremely positive impact) the average impact was increasingly negative with increasing autism severity, ranging from -3.3 (±1.7) for completely non-verbal respondents, -0.9 (±3.5) for partially verbal and -0.7 (± 3.1) for fully verbal respondents. No notable differences were found on the impact of autism on relationships with other students reported between respondents with different levels of autism severity. Additionally, a discrepancy was observed on the impact of autism on academic work/performance reported by supporters answering on behalf of an autistic person compared to autistic respondents themselves (-2.4, ± 2.9 vs. -0.9, ± 3.3 respectively).

The following sections reflect survey questions on types of education excluding home-schooling, although it is worth noting that 47.5% (n=28) of those experiencing home-schooling reported that their autism had an impact on their decision to pursue home education.

8.1. Institutional support

Respondents were asked if their educational institution supported their needs. The findings presented in this section cover a set of respondents across education levels who indicated that their needs were supported by their institution at least somewhat[8] (Table 7). Of the educational settings looked at, special educational schools were reported to meet the needs of respondents more than others, with 80% (n=52) of those who experienced special

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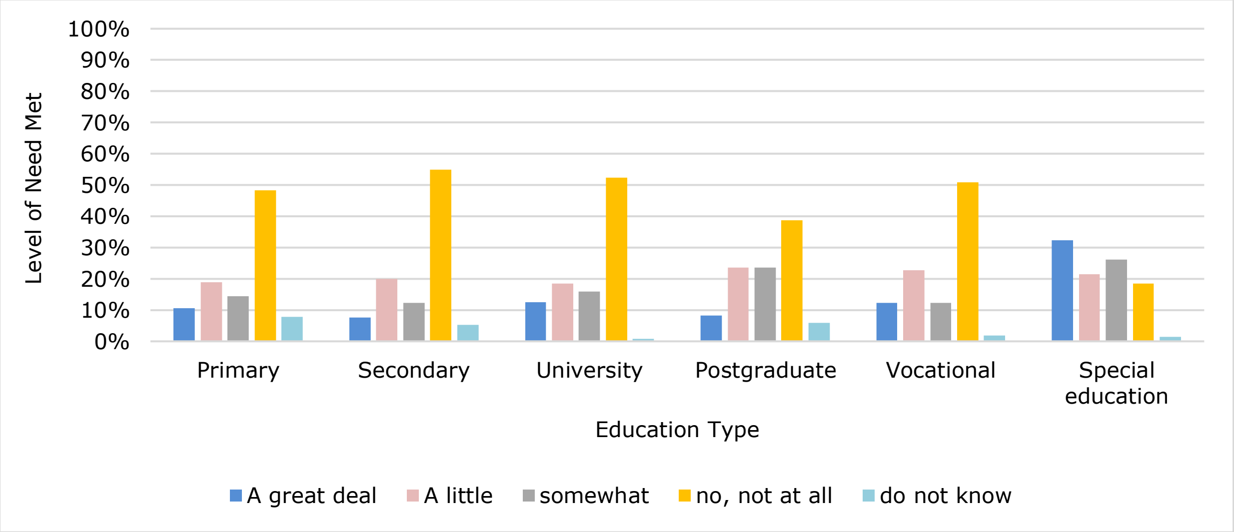
[7] *Special education is used to refer to educational institutions which use modified tools and teaching arrangements to meet the needs of children with additional support needs. Language and terms may differ across countries, for example, Special Educational Needs schools in the UK.*

[8] *Possible answers regarding whether a respondent's needs were supported by their educational institution include the following: "Yes, a great deal," "Yes, a little," "Yes, somewhat," "No, not at all," or "I do not know."*

education reporting that their needs were met at least somewhat. Secondary school had the lowest rates of respondents' needs being met - only 40% (n=114) of respondents' felt that their needs were met at least somewhat during their secondary school experience. Across all countries and education levels (excluding special education), the proportion of respondents' whose needs were met by their institution at least somewhat ranged from 40% (n=114) at secondary school level to 55% (n=47) at postgraduate level.

Italy performed consistently well at meeting respondents' needs across education levels. This is likely due to the fact that inclusive education has been required in the country by law since 1971 and fewer than 1% of Italian children with additional support needs are in segregated educational settings (Zero Project, 2016). This is consistent with survey findings as only 8% (n=2) of all Italian respondents reported experiencing special educational schools (4%, n=1) or home-schooling (4%, n=1). Conversely, in Germany more than a third of respondents felt that their needs were not met across all education levels (excluding special education). In special educational settings, 67% (n=2) of German respondents felt their needs were met at least somewhat. This is 13% lower than the survey average across countries. The literature reveals that education in Germany varies by region and parental involvement is usually limited to school choice (Van Kessel et al., 2019). For those whose needs were met by their institution, 67% (n=2) of German primary school respondents and 100% (n=5) of secondary school respondents reported needing extra involvement to acquire support (Table 8).

Figure 7. Level of need met across education types and countries.



Spain did not perform well in meeting respondents' needs at the university and postgraduate levels but performed well in all other education types, with no less than 77% of respondents' needs being supported at least somewhat in all other types of education. Literature reveals that Spain has inclusive educational policies resulting in a lack of special educational settings, at least in some regions (Fuentes et al., 2021). Our survey found, however, that 30% of Spanish respondents attended special educational schools, the highest among the study countries. France has previously been criticized for discrimination against autistic people by the Council of Europe between 2004 and 2014 (Fataliyeva, 2020). The literature states that almost 80% of French autistic children do not have access to mainstream education (Fataliyeva, 2020; Ochs, 2018). However, results from our survey show that enrolment across education types in France is similar to other countries. More than half of respondents felt that French educational institutions supported their basic needs at the primary school, university, postgraduate and vocational school level. Nevertheless, French secondary schools and special educational schools only met one third or less of respondents' basic needs. In the UK, according to the literature, most autistic individuals attend mainstream education (Rattaz et al., 2014). This is consistent with our survey findings as only 8% of UK respondents attended special educational schools (5%, n=43) or home-schooling (3%, n=22). In the USA, literature revealed that as children progressed through primary and secondary school, support decreased (Spaulding, Lerner, & Gadow, 2016). This is in contrast with our survey findings which showed that the proportion of autistic individuals whose needs were supported is consistent throughout primary and secondary school (Table 7). Across all countries, 80% (n= 101) and 79% (n=90) of primary and secondary school respondents respectively also reported that extra involvement (from themselves or supporters) was necessary to acquire support to meet their needs (Table 8). As education levels rose, the extra involvement necessary to attain support decreased; for example, of those postgraduate respondents who required support, only 36% (n=17) needed extra involvement to acquire this support. Literature from France indicates that a high rate of parental involvement is needed to attain educational support (Rattaz et al., 2014). This is not consistent with our findings as half of primary and secondary school respondents and no respondents from other education types in France reported needing extra involvement from themselves or supporters to obtain support.

Where applicable, respondents were asked what their educational support looked like. A variety of support types was reported, including one-to-one support, counselling, extra time, small unit-based teaching, sensory rooms, down time, buddy support, visual timetables, and picture exchange communication systems. One-to-one support was most commonly reported across education levels, followed by extra time and small unit-based teaching. Respondents who indicated having one-to-one support ranged from 16% (n=35) in special educational schools to 36.5% (n=16) in vocational school. Support through extra time ranged from 6.8%

(n=15) in special educational schools to 31.9% (n=38) in university. Small unit-based teaching as a type of support ranged from 5.1% (n=4) in postgraduate to 17.8% (n=8) in vocational school. Downtime was also a commonly reported type of support in primary and secondary education while counselling was common in university and postgraduate (Appendix Table 2). Overall, there was a greater variety of support received in Spain, the UK, and the USA than in Germany, France, Canada and Italy, while France and Germany had the least support available across education levels. In the UK, respondents reported a wide range of support, but most respondents' needs were not met by their educational institution (Table 7). In Spain, according to the literature, schools have spaces for individual or small-group teaching and there are many support professionals in place (speech therapists, special needs teachers, psychologists etc.) (Fuentes et al., 2021). Our survey showed similar results, with a wide variety of support reported for Spanish students across all education levels, primarily counselling and one-to-one support.

Table 7. Respondents across education levels and countries indicating that their needs were supported by their institution at least somewhat.

Education level	**Countries**								**Response by gender (% out of total respondents per gender)**		
Primary school	**Canada (*n=3)**	**France (n=20)**	**Germany (n=15)**	**Italy (n=7)**	**Spain (n=16)**	**UK (n=211)**	**USA (n=20)**	**Total (n=292)**	**Male (n=119)**	**Female (n=153)**	**Other Identity (n=20)**
Yes†	3 (100%)	11 (55%)	3 (20%)	6 (85.7%)	13 (81.3%)	81 (38.4%)	11 (55%)	128 (43.8%)	63 (53.4%)	152 (39.5%)	4 (20%)
Secondary School	**Canada (n=5)**	**France (n=19)**	**Germany (n=21)**	**Italy (n=6)**	**Spain (n=13)**	**UK (n=200)**	**USA (n=22)**	**Total (n=286)**	**Male (n=105)**	**Female (n=155)**	**Other Identity (n=25)**
Yes	2 (40%)	6 (31.6%)	5 (23.8%)	3 (50%)	10 (76.9%)	76 (38%)	12 (54.5%)	114 (39.9%)	48 (46.2%)	54 (35.1%)	12 (48%)
University	**Canada (n=2)**	**France (n=8)**	**Germany (n=7)**	**Italy (n=5)**	**Spain (n=1)**	**UK (n=118)**	**USA (n=10)**	**Total (n=151)**	**Male (n=48)**	**Female (n=90)**	**Other Identity (n=13)**
Yes	0%	5 (62.5%)	1 (14.3%)	4 (80%)	0 (0%)	54 (45.8%)	7 (70%)	71 (47%)	23 (47.9%)	41 (45.6%)	7 (53.8%)
Postgraduate	**Canada (n=2)**	**France (n=9)**	**Germany (n=0)**	**Italy (n=2)**	**Spain (n=1)**	**UK (n=67)**	**USA (n=4)**	**Total (n=85)**	**Male (n=33)**	**Female (n=46)**	**Other Identity (n=6)**
Yes	0%	5 (55.6%)	n/r‡	2 (100%)	0 (0%)	38 (56.7%)	2 (50%)	47 (55.3%)	19 (57.6%)	25 (54.3%)	3 (50%)
Vocational School	**Canada (n=1)**	**France (n=5)**	**Germany (n=6)**	**Italy (n=0)**	**Spain (n=2)**	**UK (n=39)**	**USA (n=4)**	**Total (n=57)**	**Male (n=16)**	**Female (n=34)**	**Other Identity (n=7)**
Yes	1 (100%)	3 (60%)	2 (33.3%)	n/r	2 (100%)	16 (41%)	3 (75%)	27 (47.4%)	8 (50%)	16 (47.1%)	3 (42.9%)
Special Educational School	**Canada (n=1)**	**France (n=1)**	**Germany (n=3)**	**Italy (n=1)**	**Spain (n=15)**	**UK (n=41)**	**USA (n=3)**	**Total (n=65)**	**Male (n=41)**	**Female (n=22)**	**Other Identity (n=2)**
Yes	1 (100%)	0%	2 (66.7%)	1 (100%)	14 (93.3%)	32 (78%)	2 (66.7%)	52 (80%)	33 (82.5%)	17 (77.3%)	1 (50%)

Key:

*: Total "n" reflects all responses excluding "not applicable"
†: Yes indicates "Yes, a great deal", "Yes, a little" and "Yes, somewhat"
‡: n/r indicates no responses

Table 8. Respondents across education levels and countries who indicated that extra involvement (from themselves or supporters) was necessary to acquire support.

Education level	**Countries**								**Response by gender (% out of total respondents per gender)**		
Primary school	**Canada (*n=3)**	**France (n=10)**	**Germany (n=3)**	**Italy (n=6)**	**Spain (n=13)**	**UK (n=81)**	**USA (n=11)**	**Total (n=127)**	**Male (n=63)**	**Female (n=60)**	**Other (n=4)**
Yes†	1 (33.3%)	5 (50%)	2 (67.7%)	6 (100%)	12 (92.3%)	65 (80.2%)	10 (90.9%)	101 (79.5%)	55 (87.3%)	44 (74.6%)	2 (50%)
Secondary School	**Canada (n=2)**	**France (n=6)**	**Germany (n=5)**	**Italy (n=3)**	**Spain (n=10)**	**UK (n=76)**	**USA (n=12)**	**Total (n=114)**	**Male (n=48)**	**Female (n=54)**	**Other (n=12)**
Yes	2 (100%)	3 (50%)	5 (100%)	3 (100%)	10 (100%)	56 (73.7%)	11 (91.7%)	90 (78.9%)	42 (87.5%)	39 (72.2%)	9 (95%)
University	**Canada (n=0)**	**France (n=4)**	**Germany (n=1)**	**Italy (n=3)**	**Spain (n=0)**	**UK (n=53)**	**USA (n=7)**	**Total (n=68)**	**Male (n=22)**	**Female (n=39)**	**Other (n=7)**
Yes	n/r‡	0%	1 (100%)	3 (100%)	n/r	25 (47.2%)	5 (71.4%)	34 (50%)	11 (50%)	18 (46.2%)	5 (71.4%)
Postgraduate	**Canada (n=0)**	**France (n=5)**	**Germany (n=0)**	**Italy (n=2)**	**Spain (n=0)**	**UK (n=38)**	**USA (n=2)**	**Total (n=47)**	**Male (n=19)**	**Female (n=25)**	**Other (n=3)**
Yes	n/r	0%	n/r‡	2 (100%)	n/r	14 (36.8%)	1 (50%)	17 (36.2%)	8 (42.1%)	8 (32%)	1 (33.3%)
Vocational School	**Canada (n=1)**	**France (n=3)**	**Germany (n=2)**	**Italy (n=0)**	**Spain (n=2)**	**UK (n=14)**	**USA (n=3)**	**Total (n=25)**	**Male (n=8)**	**Female (n=14)**	**Other (n=3)**
Yes	0%	0%	0%	n/r	2 (100%)	4 (28.6%)	3 (100%)	9 (36%)	4 (50%)	4 (28.6%)	1 (33.3%)
Special Educational School	**Canada (n=1)**	**France (n=0)**	**Germany (n=2)**	**Italy (n=1)**	**Spain (n=14)**	**UK (n=32)**	**USA (n=2)**	**Total (n=52)**	**Male (n=33)**	**Female (n=17)**	**Other (n=2)**
Yes	1 (100%)	n/r	2 (100%)	1 (100%)	14 (100%)	31 (96.9%)	2 (100%)	51 (98.1%)	32 (97%)	17 (100%)	2 (100%)

Key:
*: Total "n" reflects all responses excluding "not applicable"
†: Yes indicates "Yes, a great deal", "Yes, a little" and "Yes, a moderate amount"
‡: n/r indicates no responses

8.2. Discrimination

Respondents were asked if they experienced discrimination during their education. Across all countries and genders, secondary school education had the highest rate of discrimination (72%, n= 224) and postgraduate level had the lowest rate of discrimination (38%, n=38). Across all education levels except special education, females experienced discrimination at higher rates than other genders (Table 9). Excluding special education 31.6% of male respondents experienced discrimination in postgraduate settings increasing to 38% in primary school settings, while 53% of females experienced discrimination in primary school settings, increasing to 60.5% in postgraduate settings. Looking at special education settings, 60.9% of male respondents experienced discrimination (the highest level of discrimination for males) whilst 34.8% of females experienced discrimination (the lowest level of discrimination for females).

Table 9. Gender distribution of those who experienced discrimination.

	Male	Female	Other Identity	Total (across all genders†)
Primary (*n=221)	84 (38%)	118 (53%)	19 (9%)	67.6%
Secondary (n=224)	77 (34.5%)	123 (55.2%)	24 (10.8%)	71.7%
University (n=77)	27 (35.1%)	47 (61%)	3 (3.9%)	43.3%
Postgraduate (n=38)	12 (31.6%)	23 (60.5%)	3 (7.9%)	38%
Vocational School (n=40)	13 (32.5%)	22 (55%)	5 (12.5%)	64.5%
Special Education (n=23)	14 (60.9%)	8 (34.8%)	1 (4.3%)	37.1%

Key:

*: Total "n" reflects those respondents who experienced discrimination, indicated by answering either "Yes" or "Yes, I was discriminated against, but it was not known at the time that I was autistic."
†: proportion of total respondents within each type of education and across genders.

Additionally, across study countries and all education levels (excluding special education), the majority of people who experienced discrimination did not know they were autistic at the time (Appendix Table 3). For example, the majority (65%, n=40) of respondents in vocational training experienced discrimination but 83% (n=33) of those experiencing discrimination did not know they were autistic at the time (Table 10, Appendix Table 3). In primary and secondary school, females, and those with another gender identity experienced discrimination without knowing they were autistic at rates ranging from 71% to 84% (vs. 29% and 16% of females and those with another gender identity respectively who reported experiencing discrimination while knowing they were autistic). The respective male percentage was lower but still more than half, with a range of 58% to 62%. Full survey results regarding discrimination are available in Table 10 and Appendix Table 3.

In terms of discrimination prevalence across countries, primary school discrimination occurred the least in Spain and in the USA, where 38% of Spanish respondents (n=6) and 38% of American respondents (n=8) did not experience discrimination (Table 10). The highest rate of discrimination in primary school was found to be in Germany, where all respondents reported experiencing some level of discrimination. Discrimination in the secondary school setting was also lowest in Spain and highest in Germany. The majority of Spanish secondary school respondents (55%, n=6) reported that they did not experience discrimination while 95% (n=20) of German secondary school respondents reported experiencing discrimination of some level.

Key findings on education & discrimination

- Respondents' needs were typically not supported by their educational institution. Secondary schools performed the worst in meeting respondents' needs and special educational schools performed the best.
- Most respondents, particularly those who have a gender identity other than male, who experienced discrimination did not know they were autistic at the time.
- A range of different types of support are offered in educational institutions across study countries. The most common are one-to-one support followed by extra time and small unit-based teaching.
- Primary school discrimination occurred the least in Spain and in the USA, where 38% of Spanish respondents (n=6) and 38% of American respondents (n=8) did not experience discrimination.

Table 10. Discrimination experienced across education levels and countries.

Primary School	**Canada (n= 4)**	**France (n= 22)**	**Germany (n= 17)**	**Italy (n=7)**	**Spain (n=16)**	**UK (n= 254)**	**USA (n= 21)**	**Total (n=341)**
Yes*	0%	2 (9.1%)	2 (11.8%)	3 (42.9%)	5 (31.3%)	57 (22.4%)	3 (14.3%)	72 (21.1%)
Yes, but unaware†	2 (50%)	14 (63.6%)	12 (70.6%)	0%	2 (12.5%)	111 (43.7%)	9 (42.9%)	150 (44%)
No	1 (25%)	2 (9.1%)	0%	1 (14.3%)	6 (37.5%)	45 (17.7%)	8 (38.1%)	63 (18.5%)
I don’t know	1 (25%)	4 (18.2%)	3 (17.6%)	3 (42.9%)	3 (18.8%)	41 (16.1%)	1 (4.8%)	56 (16.4%)
Secondary School	**Canada (n= 6)**	**France (n= 17)**	**Germany (n= 21)**	**Italy (n= 7)**	**Spain (n=11)**	**UK (n= 226)**	**USA (n=23)**	**Total (n=311)**
Yes	1 (16.7%)	0%	5 (23.8%)	3 (42.9%)	2 (18.2%)	42 (18.6%)	5 (21.7%)	58 (18.6%)
Yes, but unaware	2 (33.3%)	12 (70.6%)	15 (71.4%)	2 (28.6%)	1 (9.1%)	122 (54%)	11 (47.8%)	165 (53.1%)
No	2 (33.3%)	3 (17.6%)	1 (4.8%)	1 (14.3%)	6 (54.5%)	38 (16.8%)	7 (30.4%)	58 (18.6%)
I don’t know	1 (16.7%)	2 (11.8%)	0%	1 (14.3%)	2 (18.2%)	24 (10.6%)	0%	30 (19.6%)
University	**Canada (n=3)**	**France (n=10)**	**Germany (n=9)**	**Italy (n=4)**	**Spain (n=1)**	**UK (n=137)**	**USA (n=14)**	**Total (n=178)**
Yes	0%	0%	0%	0%	0%	18 (13.1%)	4 (28.6%)	22 (12.4%)
Yes, but unaware	1 (33.3%)	2 (20%)	3 (33.3%)	1 (25%)	1 (100%)	44 (32.1%)	3 (21.4%)	55 (30.9%)
No	1 (33.3%)	7 (70%)	3 (33.3%)	1 (25%)	0%	53 (8.79%)	5 (35.7%)	70 (39.3%)
I don’t know	1 (33.3%)	1 (10%)	3 (33.3%)	2 (50%)	0%	22 (16.1%)	2 (14.3%)	21 (17.4%)
Postgraduate	**Canada (n=2)**	**France (n=10)**	**Germany (n=0)**	**Italy (n=2)**	**Spain (n=1)**	**UK (n=80)**	**USA (n=5)**	**Total (n=100)**
Yes	0%	1 (10%)	n/r‡	0%	0%	11 (13.8%)	0%	12 (12%)
Yes, but unaware	0%	2 (20%)		0%	0%	22 (27.5%)	2 (40%)	26 (26%)
No	1 (50%)	3 (30%)		2 (100%)	0%	32 (40%)	3 (60%)	41 (41%)
I don’t know	1 (50%)	4 (40%)		0%	1 (100%)	15 (18.8%)	0%	21 (21%)
Vocational School	**Canada (n=1)**	**France (n=4)**	**Germany (n=6)**	**Italy (n=0)**	**Spain (n=3)**	**UK (n=44)**	**USA (n=4)**	**Total (n=62)**
Yes	0 (0%)	0 (0%)	0 (0%)	n/r	0%	7 (15.9%)	0%	7 (11.3%)
Yes, but unaware	1 (100%)	2 (50%)	6 (100%)		0%	22 (50%)	2 (50%)	33 (53.2%)
No	0 (0%)	1 (25%)	0 (0%)		3 (100%)	11 (25%)	2 (50%)	17 (27.4%)
I don’t know	0 (0%)	1 (25%)	0 (0%)		0%	4 (9.1%)	0%	5 (8.1%)
Special Education	**Canada (n=1)**	**France (n=2)**	**Germany (n=2)**	**Italy (n=1)**	**Spain (n=15)**	**UK (n=38)**	**USA (n=3)**	**Total (n=62)**
Yes	0%	0%	2 (100%)	0%	3 (20%)	13 (34.2%)	1 (33.3%)	19 (30.6%)
Yes, but unaware	0%	1 (50%)	0%	0%	1 (6.7%)	2 (5.3%)	0%	4 (6.5%)
No	1 (100%)	1 (50%)	0%	0%	8 (53.3%)	19 (50%)	2 (66.7%)	31 (50%)
I don’t know	0%	0%	0%	1 (100%)	3 (20%)	4 (10.5%)	0%	8 (12.9%)

Key:

***:**Yes, and aware of their autism at the time.
†: “Yes, but unaware” reflects respondents who experienced discrimination but were unaware of their autism at the time.
‡: n/r indicates no responses

9. Employment

9.1. Employment status

Of the 451 survey respondents, 385 were aged over 16 and were asked questions around their current employment status and employment history. Of the 385 people answering, 22.6% (n=87) were in full-time employment, 11.2% (n=43) in part-time employment, 21% (n=81) unemployed, 9.4% (n=36) were still in education, 7.5% (n=29) were self-employed, 5.2% (n=20) were retired, 2.3% (n=9) were full time parents/supporters and 1.3% (n=5) were in supported employment (Table 11). Almost 20% (n=75) chose the 'other' option which included, for example, those that were retraining, those volunteering and those unable to work due to health reasons. The highest rates of full-time employment were in the US, where 42.9% of respondents reported full-time employment compared to figures between 14 and 28% in other countries. Part-time employment is more common in Canada (25%) and Italy (25%). Respondents from Spain had more chance of being in supported employment than respondents from other countries.

Of the 385 respondents answering questions on employment, 38.7% (n=149) were male, 53% (n=204) were female and 8.3% (n=32) were non-binary or had a different gender to that at birth. Women report slightly higher rates of being a full-time parent or supporter (4.4%) or in part-time employment (13.2%) (Table 11). These findings are corroborated in the literature, which suggests employment rates for autistic individuals are low. For example, in the US, autistic adults had the lowest rate of employment after high school[9] (Burgess & Cimera, 2014), and reported employment rates in other countries are also low: 13 to 22% across Canada, 15% to 16% in the UK, 25% in the US, and 50% in Germany for independently functioning autistic adults (Autism Canada, Autism Research Institute, & Pacific Autism Family Network, 2017; Dudley, Nicholas, & Zwicker, 2015; Kornblau, 2014; National Autistic Society, 2016; Vogeley, Kirchner, Gawronski, Van Elst, & Dziobek, 2013). High unemployment rates can lead to further issues, such as social isolation, stress, and concurrent conditions such as depression (Vogeley et al., 2013). Often the autistic community does express interest in being employed (Giarelli, Ruttenberg, & Segal, 2013). A German study found that those with later-

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[9] *At a rate of 63.2%, with only peers with multiple disabilities reporting a lower employment rate (62.5%). At the time of the survey, autistic adults were employed at lower rates (37.2%) than peers from all other categories, except those who were deaf/blind (30.1%) and those with orthopaedic impairments (35%) (Burgess & Cimera, 2014).*

life diagnoses were at a disadvantage for labour market participation, and that often there seems to be a mismatch between roles and qualifications, where autistic individuals are overqualified (Frank et al., 2018). Similar observations were made in an American study of young adults: they felt a mismatch between their skills and work demands, 'reporting that they had jobs rather than careers, and were unable to find work related to their college degrees' (K. A. Anderson, Sosnowy, Kuo, & Shattuck, 2018a). Some countries have efforts in place to improve unemployment numbers amongst certain groups, some which cover autistic populations too: in Spain 2% of a company's workforce has to be made up of people with specific conditions, or else they must donate to charity (Erasmus + & TRAIL Project, 2016). However, quality support for entering and/or remaining in employment seems limited: the UK Access to Work programme supports people with various conditions in seeking employment, and in the US most states cover employment services through Medicaid though most states do not have employment mechanisms specifically for autistic individuals (Erasmus + & TRAIL Project, 2016; Koffer Miller, Mathew, Nonnemacher, & Shea, 2018). A Canadian study found that the quality and benefits of employment-support services for autistic adults were perceived more positively by employment-support personnel than by autistic individuals and their families (Nicholas et al., 2018). In Germany, results from a clinical trial showed better employment outcomes for those provided with a programme for (re)integration into employment (Vogeley et al., 2013). Similar findings are reported in the UK, where supported employment efforts resulted in better employment outcomes when compared to standard care (Mavranezouli et al., 2014).

We asked those currently not in any kind of employment whether they had ever been in paid employment: of 126 individuals not currently in employment, 42% (n=53) had never been in paid employment. When those that had never been in paid employment were asked to what degree they felt autism affected decisions they have made, or been forced to make, around paid employment, it was found that autism had an average impact of 8.4 (± 2.8) on a scale from 0 (did not affect) to 10 (greatly affected), with almost 70% (n=34) choosing either 9 (*reasonably affected*) or 10 (*greatly affected*), and only 8% (n=4) choosing either 0 (*did not affect*), 1 (*affected slightly*) or 2 (*affected*).

Of the 58% (n=73) that had at one point been in paid employment prior to completing the survey, reasons for leaving paid employment included returning to further education, mental health issues, finding employment too stressful, bullying, discrimination based on autism diagnosis, lack of support, and issues related to the COVID-19 pandemic. Stereotyping, prejudice and misunderstanding within the workplace are barriers to employment, while inadequate self-advocacy and soft skills also contribute to issues in entering and remaining in the workplace (Autism Nova Scotia, 2015). Out of 20 retired respondents, 60% (n=12) retired on average, about 11 years earlier than the commonly established age of retirement in their country of residence and out of these, almost 60% (n=7) felt they had to retire early due to their autism whilst a third said that their autism played a role in their early retirement.

9.2. Impact of autism at work

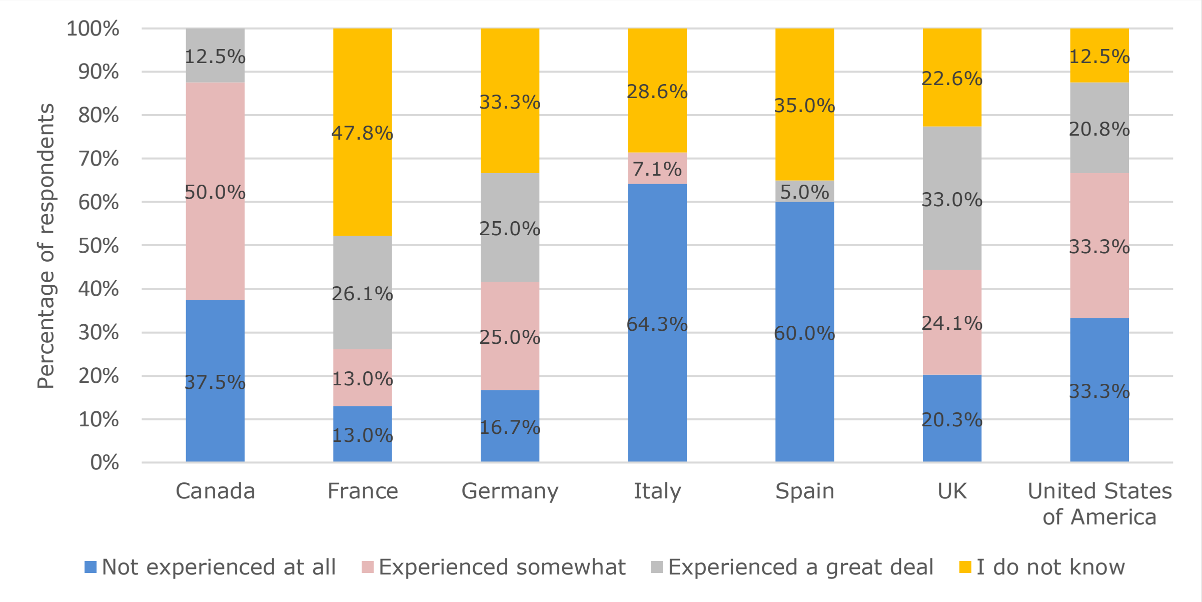
328 respondents answered questions on the positive impact of autism on their working life. 40% (n=131) of those answering did not think that autism positively impacted their working life at all, whilst over half (51%) thought that autism had a positive impact, ranging from '*a great deal of positive impact*' to '*a little positive impact*'. Reasons for the positive impact tended to focus on the respondents' ability to focus and 'hyper-concentrate', follow rules, enhanced problem-solving skills, attention to detail, and their ability to have a special insight into the lives of other autistic individuals.

326 respondents answered questions on the negative impact autism has on their working life. Respondents reported an average impact of 5.6 (±2.9) of autism on their productivity, on a scale from 0 (autism had no effect on productivity at work) to 10 (autism significantly affected productivity at work). Based on autism severity level, this impact ranged from 5.3 (±2.9) for individuals with no problem communicating verbally, 6.0 (±2.7) for those with some difficulty communicating verbally and up to 6.8 (±3.8) for those completely non-verbal. In terms of country-specific results, in Canada (6.3, ±2.6), France (7.7, ±2.6) and the US (6.2, ±2.8), respondents rated these effects above the overall country average. Overall, only 6% of respondents (n=19) thought that autism had no negative impact on their working life. Almost 90% of people thought that autism had a negative impact on their working life, ranging from '*a little*' impact (9.82%, n=32) to '*a great deal*' of impact (49.4%, n=161). Reasons for the negative impact included issues with overwhelm and sensory overload, a lack of understanding about autism in the workplace, a lack of support (Table 11), and social interaction in the workplace. Issues with social interaction included feeling isolated, bullying, difficulties networking or making friends, and difficulties communicating or expressing oneself. Many respondents highlighted it was not necessarily their autism that was having the negative impact on their work, but issues related to non-autistic colleagues/management being unable or unwilling to adapt or accept other needs and requirements.

Respondents' experience of discrimination in the workplace was generally evenly split across the categories: 25.2% stated they had not experienced discrimination at all, 22.5%

experienced some discrimination, and 27.4% experienced a great deal of discrimination. When looking at country-specific responses, respondents from Italy and Spain were less likely to have suffered from discrimination, whilst those from France, the UK and USA were more likely to have experienced discrimination in the workplace (Figure 8, Appendix Table 4). Men reported slightly less experiences with discrimination (29%), compared to women (23.6%) and people with another gender identity (18.5%).

Figure 8. Experience of discrimination in the workplace due to autism across countries.



Those that expanded on their experience of discrimination tended to experience social manipulation, bullying, exclusion from activities and preconceived ideas about autism. For example: *"At a previous job as a teaching assistant, shortly after diagnosis, I asked for reasonable adjustments. My line manager told me that I wouldn't be good enough to be a teacher because of my autism and shouldn't even bother with the training as it would waste everyone's time."*, *"A lack of empathy, people write me off as a complainer, won't listen to me or accept that I need help. There are people who find being around me uncomfortable; they will blank me completely even after we have had conversations and some will even act with hostility towards me, on our first meeting."*, *"People don't take my opinion as valid."*, *"Anything relating to social cooperation, teamwork, falling in place in hierarchical lines is difficult, and I have to have breaks and get severe migraines, and brain fog, and panic attacks, and mutism. I have to meter what I become involved with, it's a battle of doing well at work, or at home, with no winner".*

Half of respondents who had at one point been in employment reported having no support in place to allow them to succeed (Table 11). Looking across countries, respondents from France were more likely to report a lack of support (n=19, 76% of French respondents) whilst those from the USA were most likely to report a level of support in place (n=15, 65% of American respondents). Results from male and female respondents are generally similar; those with a different gender identity reported slightly higher rates of not receiving support or stating they did not know whether they received sufficient support. Those which responded either 'yes' (13.2%) or 'some' (24.5%) to whether enough workplace support was in place, reported support experienced tended to include understanding colleagues and management, adjustments or measures, one-on-one support and specialist coaching. Those that did not receive any support made a number of suggestions for support that would have made employment easier for them. For example, having an earlier diagnosis would have made accessing available support easier. Similarly, more understanding from colleagues around autism, different methods of information-sharing, alternative recruitment methods to avoid the interview process and a mentor to help them navigate the workplace (Table 12) would have positively impacted their experience of the workplace.

Key findings on employment

- Autistic employees face several challenges including but not limited to concurrent conditions, difficulty with communication and other social impairments, negative social views about autism and a lack of understanding about autism in the workplace.
- Despite a variety of types of support in place across countries, widespread quality support is limited.
- Nearly all respondents agreed that autism has a negative impact on their work life in part due to sensory overload or issues around social interaction, although 51% also thought that autism has a positive impact on their work life due to their ability to focus, and their enhanced problem-solving and attention to detail skills.
- Respondents pointed out that it is not necessarily their autism causing the negative impact on their work life but other reasons relating to colleagues and managers being unwilling to accommodate them. Addressing these aspects, in addition to participation in supported employment can improve employment outcomes for autistic people.

Table 11. Respondent employment status, impact of autism on employment and experience of workplace support, across countries and genders, where applicable.

	Employment status across countries								Response by gender (% out of total respondents per gender)		
	Canada (n = 8)	France (n = 29)	Germany (n = 28)	Italy (n = 16)	Spain (n = 29)	UK (n = 247)	USA (n =28)	Total (n =385)	Male (n = 149)	Female (n = 204)	Other identity (n = 32)
Full-time paid employed	2 (25%)	5 (17.2%)	4 (14.3%)	3 (18.8%)	8 (27.6%)	53 (21.5%)	12 (42.9%)	87 (22.6%)	38 (25.5%)	45 (22.1%)	4 (12.5%)
Part-time paid employed	2 (25%)	0%	2 (7.1%)	4 (25%)	1 (3.5%)	31 (12.6%)	3 (10.7%)	43 (11.2%)	15 (10.1%)	27 (13.2%)	1 (3.1%)
Self employed	2 (25%)	1 (3.5%)	1 (3.6%)	2 (12.5%)	0%	21 (8.5%)	2 (7.1%)	29 (7.5%)	11 (7.4%)	15 (7.4%)	3 (9.4%)
Supported employment	0%	0%	1 (3.6%)	1 (6.3%)	3 (10.3%)	0%	0%	5 (1.3%)	4 (2.7%)	1 (0.5%)	0%
Full-time parent/ supporter	0%	0%	2 (7.1%)	1 (6.3%)	2 (6.9%)	3 (1.2%)	1 (3.6%)	9 (2.3%)	0%	9 (4.4%)	0%
Retired	0%	2 (6.9%)	3 (10.7%)	0%	0%	14 (5.7%)	1 (3.6%)	20 (5.2%)	11 (7.4%)	7 (3.4%)	2 (6.3%)
Student	1 (12.5%)	2 (6.9%)	5 (17.8%)	1 (6.3%)	3 (10.3%)	20 (8.1%)	4 (14.2%)	36 (9.4%)	10 (6.7%)	18 (8.8%)	8 (25%)
Unemployed	0%	9 (31%)	4 (14.3%)	3 (18.8%)	8 (27.6%)	56 (22.7%)	1 (3.6%)	81 (21%)	38 (25.5%)	40 (19.6%)	3 (9.4%)
Other	1 (12.5%)	10 (34.5%)	6 (21.4%)	1 (6.3%)	4 (13.7%)	49 (19.8%)	4 (14.2%)	75 (19.5%)	22 (14.8%)	42 (20.6%)	11 (34.4%)

	Impact of autism on employment							
	Canada (n = 0)	France (n = 4)	Germany (n = 3)	Italy (n = 1)	Spain (n = 7)	UK (n = 30)	USA (n = 4)	Total (n = 49)
Impact on decisions about paid employment (0-10), mean (SD)	-	7.8 (2.6)	5.7 (4.9)	10 (-)	6.7 (4.1)	9.3 (1.6)	6.8 (3.9)	8.4 (2.8)
	Canada (n = 9)	France (n = 6)	Germany (n = 8)	Italy (n = 9)	Spain (n = 11)	UK (n = 103)	USA (n = 17)	Total (n = 160)
Impact on productivity in an average month (0-10), mean (SD)	6.3 (2.6)	7.7 (2.6)	5.8 (2.3)	5.6 (3.8)	4.4 (2.9)	5.4 (2.9)	6.2 (2.8)	5.6 (2.9)

	Experience of workplace support across countries								Response by gender (% out of total respondents per gender)		
	Canada (n = 8)	France (n = 25)	Germany (n = 25)	Italy (n = 14)	Spain (n = 20)	UK (n = 211)	USA (n = 23)	Total (n = 326)	Male (n = 124)	Female (n = 175)	Other identity (n = 27)
No support	4 (50%)	19 (76%)	16 (64%)	6 (42.9%)	5 (25%)	110 (52.1%)	4 (17.4%)	164 (50.3%)	59 (47.6%)	90 (51.4%)	15 (55.6%)
Some support	1 (12.5%)	4 (16%)	3 (12%)	4 (28.6%)	4 (20%)	56 (26.5%)	8 (34.8%)	80 (24.5%)	32 (25.8%)	44 (25.1%)	4 (14.8%)
Yes, enough support	3 (37.5%)	0%	3 (12%)	3 (21.4%)	8 (40%)	19 (9%)	7 (30.4%)	43 (13.2%)	18 (14.5%)	25 (14.3%)	0%
Do not know	0%	2 (8%)	3 (12%)	1 (7.1%)	3 (15%)	26 (12.3%)	4 (17.4%)	39 (12%)	15 (12.1%)	16 (9.1%)	8 (29.6%)

Table 12. Examples of support that would have made employment easier.

Canada	*Flexible hours and skills-based application along with a placement service*
Germany	*Promote understanding and knowledge about autism, strengths and weaknesses and assign individual tasks*
	Less working hours with financial compensation, more breaks, more vacation and help after a suitable job without shift work, without a lot of teamwork, without a lot of customer contact e.g., in the archive.
Spain	*Have a diagnosis at an early age and a certificate of disability*
UK	*Someone to advise on how to disclose my diagnosis at work and how to explain my additional needs.*
	An alternative to interviews as a means of recruitment.
	Organisation and planning. Support with other tasks so space in my life for employment too. Pastoral support. OT focussing on capabilities and limitations for work.
	Initially a mentor, somebody who understood how the autism affected me and therefore the impact this had on the way I could work and could act as an advocate for me until I had settled into the role. Having a named person, I could trust and could go to if I was having difficulties.
	Perhaps more visual explanations of tasks and regulations, adjustments to the work environment, understanding of my needs from colleagues (e.g., I don't like people standing too close to me). I never told any work colleagues that I suspected that I may be on the autistic spectrum, because I was afraid of their reaction, or of being judged negatively.
	I don't think it exists. No one is going to give you a job if you write you are autistic on a job application form. You will be seen as more trouble than it is worth. I was sent on a communications course, it did nothing for me as whilst understanding the principles, it didn't reduce stress or pave the way for anything better.
USA	*During my lifetime if there had been a recognition of autism as a condition, and if I had received a diagnosis early on, there would have been many options. As it was, there was nothing.*

10. Accommodation

10.1. Living arrangements

98.6% of children under 18 (total n = 71; Appendix Table 5) across all countries, live with parents or other family members who act as supporters. The only exception was found in the UK, where one respondent (1.4%) reported living independently with partners or family members with no caring responsibilities. More variation in living arrangements was observed across adult respondents (18 or over; n=376; Appendix Table 5). The largest proportion, 32.2% of adults, reported living independently with partners or family members not acting as supporters whilst 27.4% of adults continued to live with parents or other family members acting as supporters. Of these adults living with others, slightly more women reported living independently and slightly more men reported living with supporters: of all female respondents, just under a quarter live with supporters and 35.7% live independently with others, while out of all male respondents 34% reported living with supporters and 27.2% live alone. Just under 20% of adults lived independently on their own, with similar findings across women (19.1% of female respondents), men (19% of male respondents) and respondents with a different gender identity (23.3% of respondents with a different gender identity). Only 3.5% of adults across all countries reported living on their own (or with a partner) while receiving additional social support/homecare, with results for this option only observed in Germany (7.1% of country respondents), Spain (10.3%), and the UK (3.3%). 14.9% of adult respondents reported other living arrangements, including: shared flats and/or with friends, university or student accommodation, care home, in a cooperative building but independent flat, and lodger arrangements. Lastly, a small fraction of respondents live in supported accommodation (1.3%) or a group home (1.3%), with no differences across male and female respondents observed within our sample. However, a geographical division was observed whereby supported accommodation was only reported in Germany (3.6% of German respondents), the UK (1.3% of UK respondents), and the USA (3.7% of American respondents), while group home accommodation was only reported in France (3.6% of French respondents), Italy (6.3% of Italian respondents) and Spain (6.9% of Spanish respondents) (Appendix Table 5). Results from Spain are often outliers, showcasing both the highest proportion of adults (69%) living with parents or family acting as supporters and the lowest proportions (6.9%) of adults reportedly living independently with others or independently on their own. While results were more varied across the options in other countries, living with parental or family supporters was also above average in Italy (43.8%) (Appendix Table 5).

10.2. Support in finding accommodation

Respondents were asked whether they received any support in finding their current accommodation. Across all countries, 23.2% of respondents said this kind of support was not applicable to their living arrangements (e.g., based on their living arrangements they wouldn't require support in looking for accommodation, help gathering references, help with household chores or managing their household etc.) (Table 13). The findings presented here cover the remaining group of respondents (75.2%, n = 282), those who responded either yes or no to the question on whether or not support was received (Appendix Table 6). Out of this group, 80.4% of adults reported receiving no aid in finding their current accommodation. Not receiving support was slightly more common for women and "other" gender identities, while across all countries, only 19.6% of adults reported receiving support to find accommodation, namely 21% of male respondents, 9% of women, and 5% of those with other genders. All the Canadian respondents stated no support was provided, followed by 93.8% of respondents in the UK, 85.7% in France, and 81.8% in Germany. The highest rates of support reported in this group was in Spain (42.9%) and the USA (30.4%). For those under 18, the majority (73.2%, n= 71) reported that support in finding current accommodation was not applicable to them, while 25.4% reported no help, and only 1.4% received support (Table 13). When adjusted to exclude respondents for whom this type of support was inapplicable, 94.7% of respondents in all countries reported receiving no support, despite this support having been applicable to them (Appendix Table 6).

10.3. Support in living in current accommodation

Respondents were asked whether they received any support to allow them to live in their current accommodation, such as help with household chores or managing their household. Across all countries, 15.8% of respondents said this kind of support was not applicable to their living arrangements (Table 14). The findings presented here cover the remaining group of respondents (n = 307), those who responded yes or no to receiving support living in their current accommodation (Appendix Table 7). Out of this group, 70.5% of adults reported receiving no support or aid for daily living tasks. More precisely, 95.7% of French respondents stated they receive no support, followed by 84.2% of respondents in the UK. There are no comparable figures reported in the literature, although in the UK, there is compelling evidence that homelessness is considerably more common among autistic people than in the general population (Shelter Cymru, 2016).

The highest rates of support reported in this group was in Spain (50%) and the USA (44%). Across all countries, 29.6% of adults reported receiving support for living in their current accommodation. Of those who indicated they receive support, a wide-ranging list of support was highlighted including, financial management, nanny or childcare, support with cooking, cleaning, housework, and/or shopping, dog walking, communication with external bodies like utility companies, emotional or mental health support, and accessing healthcare. Some respondents indicated these were private costs or were provided through unofficial supporters, but it is not clear to what degree publicly provided support is available. Most respondents under 18 (68.1%) reported the receipt of current support for their accommodation was not applicable, while 25% received no help, and only 5.6% reported receiving support (Table 14).

10.4. Independent living

Respondents were asked whether they felt autism has affected their ability to live independently. Among adult respondents (n=372), 52.7%, felt that autism had affected their ability to live independently (Table 15). Italy, Spain, and the USA fell below this average, while the UK was higher at 59.3%. Common themes raised by those who said autism had an impact on independent living were wide-ranging but included: structuring or completing housework or daily organization tasks (e.g., responding to mail), communication with external people (home or car related issues or phone conversations), cooking, time management, decision-making, finances and/or budgeting, and self-care. Other issues raised were related to loneliness and isolation, and the effect of autism on the ability to earn enough money to live independently. 20% of adults felt autism had not affected their lives to date but that it may in the future, a worry slightly more common in female respondents (23.2%) than male (15.9%) or other gender (6.9%) respondents. These worries were higher in Germany (25%), Spain (34.5%), and the USA (29.6%). 28.2% of respondents stated autism had not affected their ability to live independently, which is more common in Canada (37.5%), Italy (56.3%), and the US (37%). Respondents were also asked whether they would like to live more independently than they currently do (Appendix Table 8). Over a fifth of respondents under 18 (n = 68, 22.1%) said they would like to live more independently, with 26% of male respondents and 15% of female respondents responding as such. 70.6% stated not right now but potentially in the future, with 72% of male respondents, 65% of female respondents, and all non-binary respondents responding as such. Only 7.4% of respondents under 18 did not express this desire, more commonly amongst female respondents. Half of those with the desire to live more independently were between the ages of 15 and 17. 31.3% of adults (n = 358) said they would like to live more independently than they currently do. Results in Canada (12.5%) and Spain (18.5%) were below this country average. Of those who indicated they would like to live more independently, the following reasons or goals were reported: a feeling of stability in their accommodation without threat of eviction, possibly even supported housing, a chance for sensory need accommodation, living close to a support system, such as friends or family, employment, with the potential for marriage, relationships, and enjoyment of life, and better income and financial independence. To achieve this, respondents indicated the following type of supports would be useful: support with housework/chores/paperwork, or a cleaner, time-management, more stable or supported housing (e.g., association over rental), communication with landlords/contracting, post/mail support, autism-friendly workplaces, and income and/or finance support. 24.3% of adults said they would not like to live more independently than they currently do but may in the future. This was higher in Canada (37.5%), Germany (44.4%), and Spain (51.9%) and lower in Italy (12.5%). 44.4% of adults said they would not like to live more independently, with a greater proportion of respondents stating this in Canada (50%), Italy (56.3%), the USA (63%).

Key findings on accommodation

- Across all study countries, almost all child respondents live with family who act as supporters. In the adult population, the largest proportion of respondents reported living with family who do not act as supporters while the next largest proportion reported living with family who act as supporters.
- Support in finding accommodation is not widely available and those who identify as a gender other than male report less support in finding accommodation. Some support in finding accommodation is available in the US and Spain, but with rates still under 50%.
- Female adults and children were less likely to report that their autism impacted their ability to live independently than other genders. About a third of adult respondents report wanting to live more independently than they do now.

Table 13. Support received to find accommodation for both adults and children across countries.

	Support received across countries							
Adults	**Canada (n = 8)**	**France (n = 29)**	**Germany (n = 28)**	**Italy (n = 16)**	**Spain (n = 29)**	**UK (n = 238)**	**USA (n = 27)**	**Total (n = 375)**
• Yes	0%	3 (10.3%)	4 (14.3%)	3 (18.8%)	9 (31%)	11 (4.6%)	7 (25.9%)	37 (9.9%)
• No	6 (75%)	18 (62.1%)	18 (64.3%)	9 (56.3%)	12 (41.4%)	166 (69.2%)	16 (59.3%)	245 (65.3%)
• Not applicable	2 (25%)	7 (24.1%)	6 (21.4%)	2 (12.5%)	7 (24.1%)	59 (24.6%)	4 (14.8%)	87 (23.2%)
• I do not know	0%	1 (3.4%)	0%	2 (12.5%)	1 (3.4%)	2 (0.8%)	0%	6 (1.6%)
Children	**Canada (n = 0)**	**France (n = 3)**	**Germany (n = 7)**	**Italy (n = 1)**	**Spain (n = 10)**	**UK (n = 47)**	**USA (n = 3)**	**Total (n = 71)**
• Yes	0%	0%	1 (14%)	0%	0%	0%	0%	1 (1.4%)
• No	0%	1 (33%)	1 (14%)	1 (100%)	4 (40%)	10 (21%)	1 (33%)	18 (25.4%)
• Not applicable	0%	2 (67%)	5 (71%)	0%	6 (60%)	37 (79%)	2 (67%)	52 (73.2%)
• I do not know	0%	0%	0%	0%	0%	0%	0%	0%

Table 14. Current support for living arrangements for both adults and children across countries.

	Receipt of support across countries							
Adults	**Canada (n = 8)**	**France (n = 29)**	**Germany (n = 28)**	**Italy (n = 16)**	**Spain (n = 29)**	**UK (n = 237)**	**USA (n = 27)**	**Total (n = 374)**
• Yes	3 (37.5%)	1 (3.4%)	6 (21.4%)	4 (25%)	9 (31%)	31 (13.1%)	11 (40.7%)	65 (17.2%)
• No	5 (62.5%)	22 (75.9%)	17 (60.7%)	10 (62.5%)	9 (31%)	165 (69.6%)	14 (51.9%)	242 (63.9%)
• Not applicable	0%	6 (20.7%)	5 (17.9%)	1 (6.3%)	7 (24.1%)	39 (16.5%)	2 (7.4%)	60 (15.8%)
• I do not know	0%	0%	0%	1 (6.3%)	4 (13.8%)	2 (0.8%)	0%	7(1.8%)
Children	**Canada (n = 0)**	**France (n = 3)**	**Germany (n = 7)**	**Italy (n = 2)**	**Spain (n = 10)**	**UK (n = 47)**	**USA (n = 3)**	**Total (n = 72)**
• Yes	0%	0%	1 (14.3%)	0%	0%	2 (4.3%)	1 (33.3%)	4 (5.6%)
• No	0%	1 (33.3%)	2 (28.6%)	2 (100%)	4 (40%)	9 (19.1%)	0%	18 (25%)
• Not applicable	0%	2 (66.7%)	4 (57.1%)	0%	6 (60%)	35 (74.5%)	2 (66.7%)	49 (68.1%)
• I do not know	0%	0%	0%	0%	0%	1 (2.1%)	0%	1 (1.4%)

Table 15. Impact of autism on the ability to live independently for both adults and children across countries and gender.

	Autism affecting living independently								Response by gender (% out of total respondents per gender)		
Adults	**Canada (n = 8)**	**France (n = 28)**	**Germany (n = 28)**	**Italy (n = 16)**	**Spain (n = 29)**	**UK (n = 236)**	**USA (n = 27)**	**Total (n = 372)**	**Male (n = 145)**	**Female (n = 198)**	**Other identity (n = 29)**
• Yes	4 (50%)	15 (53.6%)	15 (53.6%)	4 (25%)	9 (31%)	140 (59.3%)	9 (33.3%)	196 (52.7%)	82 (56.6%)	95 (48%)	19 (65.5%)
• Not to date, but potentially in the future	1 (12.5%)	6 (21.4%)	7 (25%)	3 (18.8%)	10 (34.5%)	36 (15.3%)	8 (29.6%)	71 (19.1%)	23 (15.9%)	46 (23.2%)	2 (6.9%)
• No	3 (37.5%)	7 (25%)	6 (21.4%)	9 (56.3%)	10 (34.5%)	60 (25.4%)	10 (37%)	105 (28.2%)	40 (27.6%)	57 (28.8%)	8 (27.6%)
Children	**Canada (n = 0)**	**France (n = 3)**	**Germany (n = 7)**	**Italy (n = 2)**	**Spain (n = 10)**	**UK (n = 45)**	**USA (n = 3)**	**Total (n = 70)**	**Male (n = 48)**	**Female (n= 20)**	**Other identity (n = 2)**
• Yes	0%	2 (66.7%)	4 (57.1%)	1 (50%)	7 (70%)	18 (40%)	1 (33.3%)	33 (47.1%)	25 (52.1%)	7 (35%)	1 (50%)
• Not to date, but potentially in the future	0%	1 (33.3%)	3 (42.9%)	1 (50%)	3 (30%)	25 (55.6%)	2 (66.7%)	35 (50%)	22 (45.8%)	12 (60%)	1 (50%)
• No	0%	0%	0%	0%	0%	2 (4.4%)	0%	2 (2.9%)	1 (2.1%)	1 (5%)	0%

11. Supporters

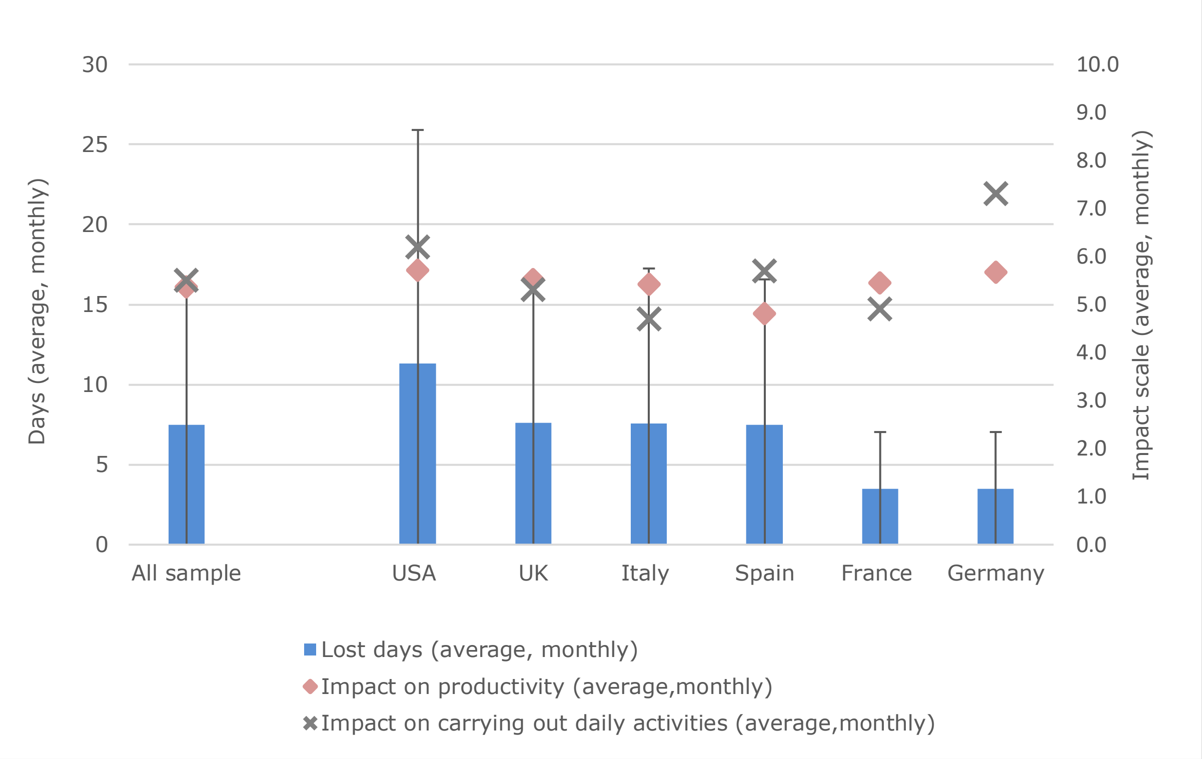
11.1. Sample size and response rate

Of the 451 people participating in the survey, 175 were supporters (either on behalf of an autistic person or alongside an autistic person). 169 of these supporters adequately completed the section of the survey that explored issues specific to supporters, namely from the UK (54%, n=91), USA (5%, n=8), Canada (1%, n=2), France (6%, n=10), Italy (8%, n=14), Germany (6%, n=10) and Spain (20%, n=34). The majority (22%) were full-time parents or supporters of autistic individuals (whether children or adults), full-time paid employed (21%), followed by part-time paid employed (20%), retired (9%), self-employed (7%) and student (6%) (Table 16), and the average age of the autistic individual they support was 25.6 (±16.1) years. In addition, of those that were full-time parents or supporters of an autistic person (n=41), 63% said that they exited paid employment entirely to care for this individual.

Of those where applicable (n=110), 41% felt their current, or most recent, employer did not provide sufficient support "at all" in light of the fact that they are a parent (or supporter) of an autistic child, 38% felt that sufficient support was "somewhat" provided and 21% felt that "a great deal" of support was provided, ranging from 50% (n=3) in the USA, 26% (n=14) in the UK, 18% (n=5) in Spain and 10% (n=1) in Italy, to 0% in Canada, France and Germany. In terms of work productivity losses, among all full-time, part-time and self-employed supporters (n=91), 71% reported missing at least one day from work due to caring for an autistic individual, ranging from 67% (n=32) in the UK, 68% (n=17) in Spain, 82% (n=9) in Italy, and 100% (n=2) in France, 100% (n=2) in Germany and 100% in USA (n=3). It was demonstrated that across all countries, an average of 7.5 (±8.7) days are lost during a typical month due to caring for an autistic person, ranging from as high as 11.3 (±14.6) days for supporters of autistic individuals in the USA, to as low as 3.5 (±3.5) for those in Germany (

Figure 9). Among those employed at any level (full/part-time or self-employed), on a self-rated productivity impairment scale from 0 (caring for an autistic person had no effect on work productivity) to 10 (caring for an autistic person completely affected work productivity), the average score was 5.4 across all countries, with little to no fluctuation between country specific scores (e.g., ranging from 5.7 in the USA and Germany to 4.8 in Spain) (Figure 9). Our findings are corroborated by relevant literature in France, suggesting that most parents, almost exclusively mothers, have to reduce or stop their work to devote themselves to the education of their autistic child (Prado, 2012; Vaincre L'Autisme, 2013). No specific figures have been reported for UK supporters of autistic people although, as our findings also demonstrate, parents raising an autistic child have a significant need to sacrifice elements of their career in order to ensure their child is provided with needed medical and educational services (Zablotsky, Anderson, & Law, 2013).

Figure 9. Supporters' average productivity losses per month, and average, monthly impact of caregiving on work productivity and carrying out daily activities.



For those where applicable (n=166), only 37% (n=61) reported that they receive or have received some financial support from the government due to caring for an autistic person, averaging €572 (±159) per month across all countries. More precisely, all supporters respondents in Canada (n=2) reported receiving an average of €852 (±258) per month, followed by 50% (n=5) of supporters in Germany receiving an average of €661 (±246) per month, 42% (n=14) of supporters in Spain receiving an average of €418 (±244), 40% (n=36) of supporters in the UK receiving an average of €416 (±458) per month, 25% (n=2) of supporters in the USA receiving an average of €657(±0) per month, 10% (n=1) of supporters in France receiving an average of €500 (±0) per month, and 8% (n=1) of supporters in Italy receiving an average of €500 (±0) per month. Additionally, of those who did not report any financial support from the government (n=102) only about a third (34%, n=35) feel that receiving financial support would have definitely improved their life as a supporter for an autistic person, 32%, (n=33) believe that it would help “somewhat” and about 15% (n=15) felt that receiving financial help would not improve their life as a supporter at all, even though among the latter only about 1% (n=2) were full-time paid employed.

11.2. Quality of Life outcomes for supporters

The majority of supporters (65%, n=108) reported caring for an autistic person has both a positive and a negative impact on their well-being and QoL, while 24% (n=40) and 5% (n=8) said that it has only a negative and only a positive impact respectively. Finally, no impact was reported by 5% (n=9) of respondents. For those who reported a positive impact, this was primarily around aspects such as having a “different perspective in life” (31%) and greater understanding/compassion/appreciation for others and life (22%), among others (Figure 10). Aspects of QoL and well-being that are negatively affected include impact on mental health (12%), lack of sleep (12%) and lack of time to pursue personal endeavours (11%), among others (Figure 10). Literature has also suggested that the impact of caring for an autistic child on parents’ career and family life and on household income negatively affects their QoL (Cappe, Poirier, Sankey, Belzil, & Dionne, 2018; Hand et al., 2018). Additionally, caring for an autistic child or individual can have a negative impact on mental health, including increased stress and depression rates (Cohrs & Leslie, 2017; Craig et al., 2016; Dudley & Emery, n.d.; Herrema et al., 2017), as well as on emotional and physical health (Rattaz, Michelon, Roeyers, & Baghdadli, 2017). Furthermore, studies from the UK corroborate our results showing that parents/supporters may also exhibit lower QoL outcomes due to: i) social exclusion and isolation because of their adult autistic children (Marsack & Samuel, 2017), ii) the burden of poor sleep quality (Johnson et al., 2018) and iii) less engaged, balanced, and cooperative relationship with partner or spouse (Hartley et al., 2017). Nevertheless, as our results also demonstrate, supporters of autistic individuals may also exhibit increased compassion and understanding for others, which in turn has been reported to have a positive impact on couple relationships (Hartley et al., 2017).

Supporters were also asked to rate how they feel about various aspects of caring. Out of 166 responses, aspects contributing to the highest proportion of constant feelings of burden and fear included fear about what the future holds for the person they care for (56%, n=93), followed by the feeling that the person they care for is dependent on them (54%, n=89) (Appendix Figure 4). Finally, on a self-rated health scale from 0 (worst health possible) to

100 (best health possible), supporters rated their average physical and mental health as 62 (±23), although country-specific discrepancies were observed, ranging from as high as 74 (±17) in the USA and 70 (±19) in Spain and as low as 55 (±29) in France and 54 (±26) in Germany (Table 16).

Literature from the USA confirms our findings that parents' primary concerns are for their child's future security, safety, and QoL (Sosnowy, Silverman, & Shattuck, 2018). Similarly, in the UK, "preparedness for the future" for the autistic adult has also been reported to contribute towards supporters worry, anxiety and stress (Herrema et al., 2017). Additionally, our results are consistent with findings from the literature demonstrating that the way parents feel about their child's autonomy level, as well as the overall feeling of threat or loss that the child's autism poses for the family's situation also has a negative impact on their QoL (Cappe et al., 2018). Finally, our country specific results about the overall physical and mental health status of supporters in France are consistent with findings arising from a study of parents caring for their autistic children in France, which demonstrated that nearly 70% of parents experience a high and/or moderate impact on both physical and emotional health due to caring for an autistic child (Rattaz et al., 2017).

Key findings on supporters

- 71% of full-time, part-time and self-employed supporters reported missing on average 7.5 (±8.7) days from work per typical month due to caring for an autistic person.
- On a work productivity impairment scale from 0 (no effect on work productivity) to 10 (completely affected work productivity), average productivity impairment was 5.4.
- 37% of supporters receive / have received some financial support from the government due to caring for an autistic person, averaging €572 (±159) per month.
- 34% of supporters felt that financial support would have definitely improved their life as a supporter and about 15% said it would not improve their life at all.
- Caring for an autistic person impacted QoL both positively and negatively for 65% of supporters. QoL aspects positively impacted include, a "different perspective in life" and greater understanding/compassion for others (31% and 22% of supporters respectively). QoL aspects negatively impacted include mental health, lack of sleep and lack of time to pursue personal endeavours (12%, 12% and 11% of supporters respectively).

- On a health status scale from 0 (worst health possible) to 100 (best health possible), supporters rated their average physical and mental health as 62 (±23).

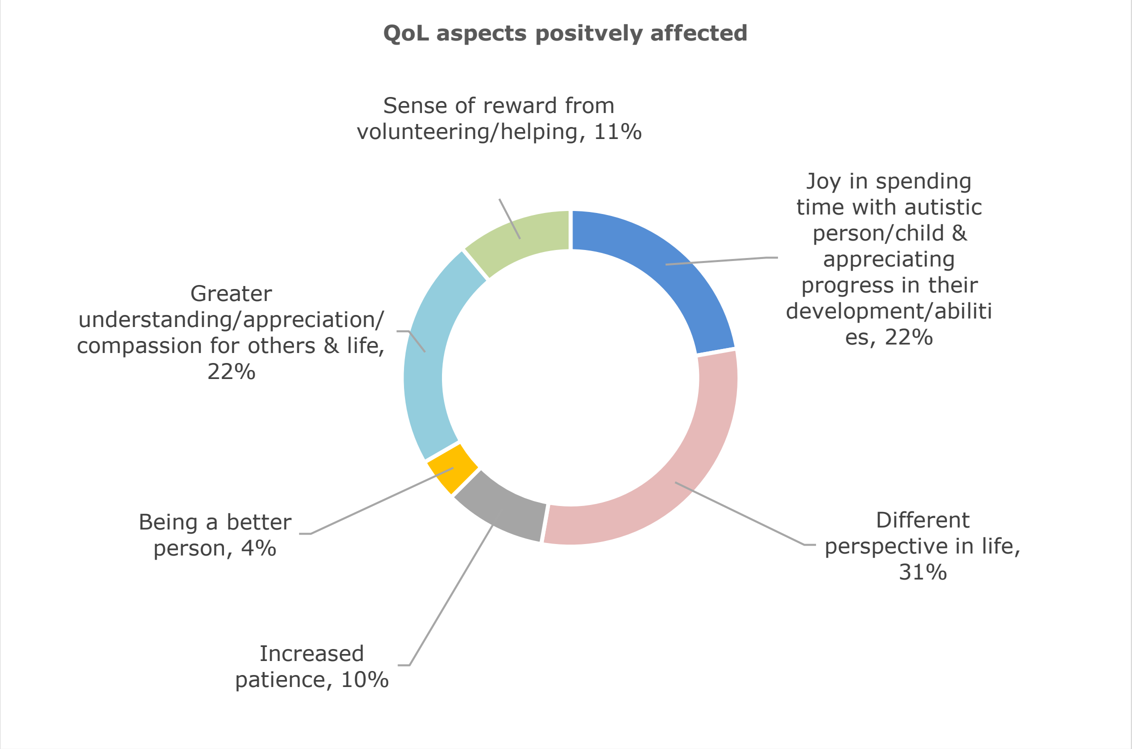
Table 16. Supporters' QoL and employment characteristics.

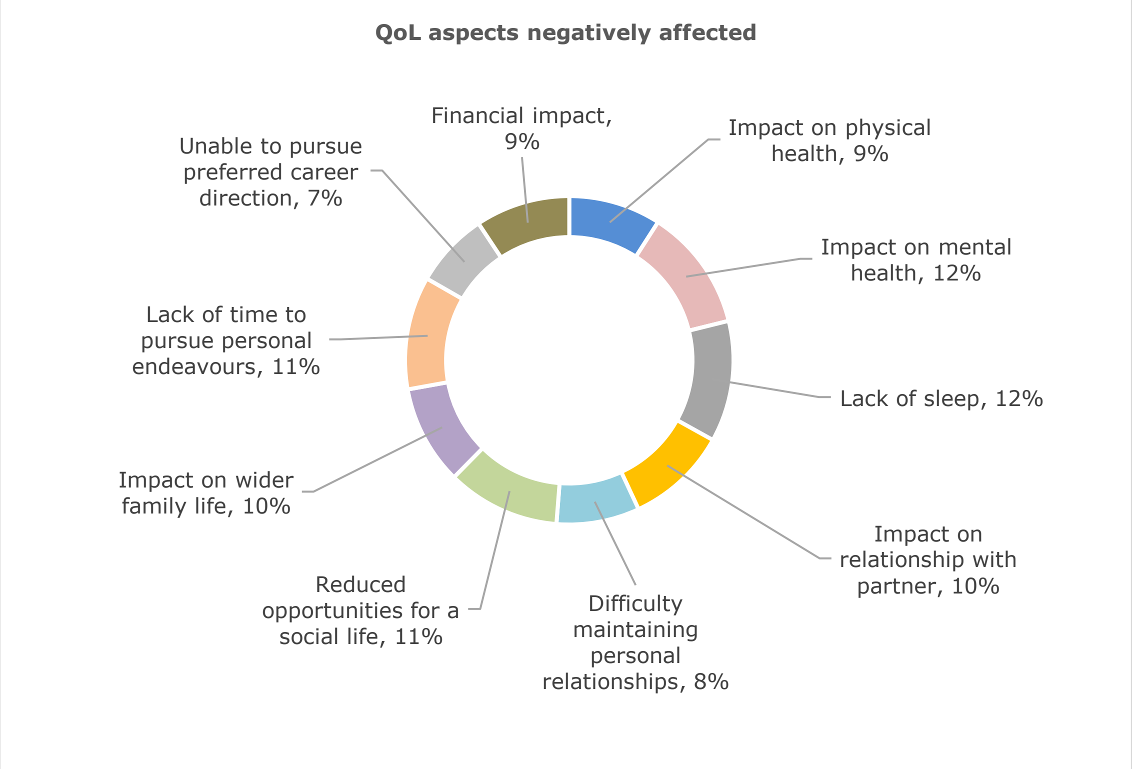
	Canada (n=2)	France (n=10)	Germany (n=10)	Italy (n=13)	Spain (n=35)	UK (n=91)	USA (n=8)	Total (n=169)
QoL characteristics								
Physical & mental health status (0; worst health possible to 100; best health possible), mean (SD)	60 (42)	55 (29)	54 (26)	63 (25)	70 (20)	60 (23)	74 (17)	62 (23)
Employment characteristics								
	Canada (n=2)	**France (n=11)**	**Germany (n=12)**	**Italy (n=15)**	**Spain (n=36)**	**UK (n=104)**	**USA (n=9)**	**Total (n=189)**
Employment status, n (%) *								
• Full-time paid employed	0%	2 (18.2%)	1 (8.3%)	6 (40%)	13 (36.1%)	15 (14.4%)	2 (22.2%)	39 (20.6%)
• Part-time paid employed	0%	0%	1 (8.3%)	3 (20%)	7 (19.4%)	26 (25%)	1 (11.1%)	38 (20.1%)
• Self-employed	0%	0%	0%	1 (6.7%)	5 (13.9%)	7 (6.77%)	1 (11.1%)	14 (7.4%)
• Full-time parent/supporter	0%	3 (27.2%)	5 (41.6%)	2 (13.3%)	5 (13.9%)	25 (24%)	1 (11.1%)	41 (21.7%)
• Retired	0%	2 (18.2%)	1 (8.3%)	0%	3 (8.3%)	10 (9.6%)	1 (11.1%)	17 (9%)
• Student	0%	0%	2 (16.7%)	1 (6.77%)	0%	7 (6.77%)	2 (22.2%)	12 (6.3%)
• Unpaid volunteer	0%	0%	1 (8.3%)	1 (6.7%)	0%	7 (6.7%)	0%	9 (4.7%)
• Other	2 (100%)	4 (36.4%)	1 (8.3%)	1 (6.7%)	3 (8.3%)	7 (6.7%)	1 (11.1%)	19 (10%)

Key: *More than one option can apply for each respondent; percentages reflect proportion out of the total number of respondents.

Note: n=Number of respondents, SD=Standard Deviation

Figure 10. Aspects of supporters' QoL and well-being that have been positively and negatively impacted by providing care for an autistic person.





12. Clinicians' survey

12.1. Responses and sociodemographic data

97 clinicians were contacted, of whom 96% (n=93) opened the survey link and 21% (n=20) adequately completed the survey for analysis. The countries of practice included: Canada (15%, n=3), France (20%, n=4), Italy (20%, n=4), and the UK (45%, n=9). The majority of respondents work both in adult and children care (45%, n=9), followed by children/young people (40%, n=8) and adult care only (15%, n=3), and are primarily based in the public sector (45%, n=9) or both public and private sector (35%, n=7). Participating clinicians were involved/represented a wide range of autism care related areas including diagnosis/assessment (70%, n=14), clinical services (80%, n=16), therapy provision (50%, n=10), social care (10%, n=2) and "Other" (25%, n=5) including advocacy, research, professional learning, and staff training.

12.2. Diagnostic pathways and practices

Fourteen clinicians responded to diagnostic related questions. According to their experience the average waiting time for a diagnostic assessment for autism is 14 months, which is perceived as an "extremely unacceptable" or "somewhat unacceptable" by 57% (n=8) and 43% (n=6) of clinicians, respectively. According to clinicians, delayed diagnostic process in autism can have multiple consequences including delays in accessing appropriate interventions and services, with subsequent educational, employment and financial implications and increased stress for autistic people and their families (Box 1).

Box 1. Clinicians' views on the impact of delayed diagnosis process on autistic people and their families.

- *"More stress for autistic people and supporters and delay in access to therapies and services"*
- *"Significant losses in education, family distress and emotional difficulties for the child."*
- *"Delayed intervention or protracted inappropriate treatments and supports."*
- *"Delays in commencing therapy, and increased risk of challenging behaviours developing."*
- *"Limited access to financial, educational or employment support and negative impact on personal relationships."*
- *"Delay in appropriate treatment and delay in therapies and social welfare benefits."*
- *"[…] Delay in diagnosis means a delay in being able to access appropriate services."*

Most clinicians (60%, n=12) reported that an MDT is always involved in diagnosing autism, although two clinicians practicing in England and France reported that this is not always possible and that it is only involved for a child but not for adults. All clinicians reported that formal diagnostic tools are generally used for the diagnosis of autism; the majority of clinicians use Autism Diagnostic Observation Schedule (ADOS/ADOS-2) (86%, n=12), followed by Autism Diagnostic Interview (ADI) and/or ADI-Revised (ADI-R) (57%, n=8), Diagnostic Interview for Social and Communication Disorders (DISCO) (14%, n=2), Developmental, Dimensional and Diagnostic Interview (3DI) (14%, n=2), Childhood Autism Rating Scale (CARS) (7%, n=1), and other tools such as AQ60 (7%, n=1), EQ60 (7%, n=1), Vineland (7%, n=1) and Italian validated versions (7%, n=1). Finally, all clinicians reported that there are national and/or regional clinical guidelines in place for the diagnosis of autism, although 86% (n=12) said that diagnostic guidelines are only adhered to by clinicians some of the time, as opposed to all of the time (14%, n=2), while 64% (n=9) reported that there are no incentives of any kind in place for the guidelines to be followed.

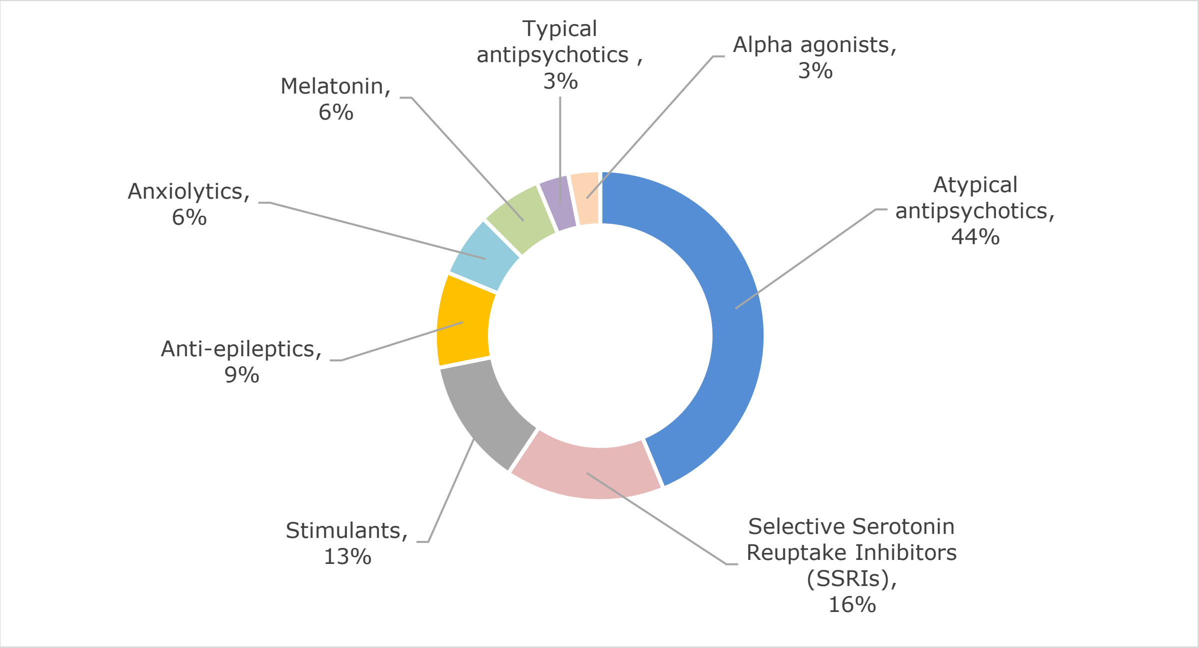
12.3. Pharmacological management and treatment pathways

In terms of interventions for managing autism, the most commonly used intervention by clinicians is SSGs (90% of clinicians, n=18), followed by CBT (85%, n=17) and Applied Behavioural Analysis (ABA) therapy (80%, n=16). Less common interventions include VBT (55%, n=11), RDI (30%, n=6), Developmental and Individual Differences Relationship (DIR) Therapy (25%, n=5) and other interventions (25%, n=5) such as; i) unspecific neurodevelopmental approaches, ii) low level support and workshops - groups like problem solving and mindfulness, iii) meetings with employers, psychologists, support workers at short notice for specific problems, iv) advocacy, peer and carer support programs and v) Early Start Denver Model (ESDM) therapy. According to 79% of clinicians, only some of these interventions/therapies are included in healthcare coverage, while 35% (n=7) of clinicians said that patients can usually self-refer themselves, 35% (n=7) that they need an official referral from a healthcare professional to access therapy and 15% (n=3) that they need an official referral for public services, but they can self-refer for behavioural therapy/intervention in private clinics. 55% (n=11) of clinicians reported that interventions such as CBT and SSGs are easily accessible for autistic people who want to utilise them, but a significant proportion (45%, n=9) reported that these services are not easily accessible. Reasons that impede accessibility include, among others, limited availability of trained practitioners and long waiting times to access. For example, *"Mental health professionals are not specifically trained to support autistic individuals"*, *"Behavioural therapies are expensive and minimally covered by the National Health*

System with long waiting lists, there are not enough specialized practitioners., "There are few well trained professionals who can deliver CBT to autistic people."

In terms of pharmacological therapy, 15 clinicians responded and said that the most commonly used medications to manage concurrent conditions in autism are atypical antipsychotics (i.e., risperidone, quetiapine, aripiprazole) (44%), Selective Serotonin Reuptake Inhibitors (SSRIs) (16%) and stimulants, (i.e., Methylphenidate) (13%), among others (Figure 11).

Figure 11. Most commonly used medication for the pharmacological management of concurrent conditions in autism according to clinicians.



10% (n=2) of clinicians said that a problem of over-medication of autistic people exists, 10% (n=2) said it does not exist, while the majority 68% (n=13) reported that it exists but only to a certain degree. Finally, when asked about their thoughts on the development and implementation of drugs which are thought to improve social communication in autistic people (e.g., Balovaptan) clinicians expressed mixed perspectives (Box 2).

Box 2. Clinicians' thoughts on the development and implementation of drugs which are thought to improve social communication in autistic people.

More favorable responses

- *"Any scientific advancement is a welcomed step."*
- *"Absolutely in favour."*

Less favorable responses

- *"[…] I believe it is better to treat social difficulties through social skill groups. Medication should only be used if all other options have failed, and the autistic person is suffering from their social communication difficulties."*
- *"I can't imagine that a single drug is going to be a replacement for teaching the complexities of social interactions, it would not be something that I would recommend to my clients."*
- *"[…] The already long story of pharmacotherapy of autism and related disorders shows that this type of hope has emerged regularly in the last 20 years with very small positive outcomes for the patients and their families. As everybody I would be very interested in a drug which would efficiently improve social communication in autistic people or at least some of them, if autism covers many different disorders. Meanwhile, ethics should be in place to avoid the emergence of regular fake news playing with this very heartfelt hope and the effect they may have on individuals and their family."*
- *"I don't see how a drug can improve social communication as it is a cognitive deficit."*

12.4. Funding, delivery and quality of care

On a scale from 0 (not at all effective) to 10 (very effective), clinicians rated a number of social care systems for autistic people, such as education, financial and housing support and it was shown that on average, the effectiveness of these systems stands at 4 (Figure 12). In terms of out-of-pocket expenses, 78% (n=14) of clinicians reported that autistic people and/or their families pay user charges for particular aspects of their care/management. The main aspects driving these expenses, as listed by the clinicians are additional intervention (93%, n=13), behavioural therapy (76%, n=11), specialist education (29%, n=4) and diagnosis (21%, n=3). According to 74% (n=14/19) of clinicians, government-funded financial assistance is available for autistic individuals and for those caring for autistic individuals, including schemes for tax discounts and disability allowances (Table 17).

Figure 12. Average effectiveness of social care systems for autistic people, as rated by participating clinicians on a scale from 0 (not at all effective) to 10 (very effective).

Table 17. Examples of government funded schemes available for autistic individuals, according to clinicians across the study countries.

Country of practice	Government-funded financial assistance for autistic individuals	Government-funded financial assistance for those caring for autistic individuals
Canada	• *Several programs, some based on income and some on disability level* • *Tax discount*	• *Tax discount*
France	• *Financial aid is available.* • *Specific and non-specific pensions for disabled children and adults*	• *Financial aid is available, but the application procedure is quite complicated.* • *Specific and non-specific pensions for supporters of disabled children and adults*
England	• *For education and social care provision for severe autism, disability allowances can be claimed* • *Personal Independence Allowance*	• *Carers' allowance is available*
Italy	• *Diagnosis and therapy at regional level (significant differences among regions)* • *Support available according to severity and not homogeneous through different regions* • *Autistic people benefit of financial support according to the severity of the disorder and the presence of concurrent conditions.*	• *Part at national, part a regional level (significant regional differences)* • *Relatives benefit of three paid days per month*

In terms of transitioning from child to adult autism care and management when a child reaches the age 18, 68% (n=13) of clinicians reported that the respective transitioning system in their country is only slightly effective, moderately effective (10%, n=2) or not at all effective (21%, n=4). Finally, different aspects of autism care and management were found to work well and/or need improvement across countries (Table 18).

Key findings from clinicians

- Clinicians reported an average wait of 14 months for autism diagnostic assessments.
- All clinicians reported that national/regional guidelines for the diagnosis of autism exist, although 86% said that diagnostic guidelines are not always adhered to by clinicians.
- 79% of clinicians said that only some interventional therapies are included in healthcare coverage, while 45% reported that these services are not easily accessible due to limited availability of trained practitioners and long waiting times to access.
- Most prescribed medications to manage concurrent conditions in autism are atypical antipsychotics, SSRIs and stimulants (44%, 16% and 13% of clinicians respectively).
- 78% of clinicians reported that a problem of over-medication for autistic individuals exists at least to a certain degree.
- On a scale from 0 (not at all effective) to 10 (very effective), clinicians rated the effectiveness of social care systems for autistic people as 4.3 on average.
- Key aspects driving private expenses in autism include interventions, behavioural therapy, special education and diagnosis (93%, 76%, 29%, and 21% of clinicians respectively).
- Clinicians reported that the adult transitioning system for autistic children in their country is only slightly, moderately or not at all effective (68%, 10% and 21% of clinicians respectively).

Table 18. Clinicians' personal views on aspects of autism care and management that work well and those that need improvement in their country of practice.

Country of practice	What do you think works well in your country of practice in terms of autism care considering both assessment and post-assessment processes?	What do you think needs improvement in your country of practice in terms of autism care considering both assessment and post-assessment processes?
Canada	• *"Publicly funded assessment, well developed guidelines, medical management better than many places but needs improvement."* • *"Most diagnostic services in hospital."*	• *"No adult sector to speak of; transition is very hard; waiting lists for access to behavioural services; schools not integrated into the therapy systems."*
France	• *"There is a current emphasis on providing early assessment and intervention, but the waiting lists are still very long."* • *"Progressive increase in the number of health professionals trained in autism."* • *"Early assessment."* • *"On average in diagnosis, assessment and care and in some aspects of education."*	• *"More care service provider."* • *"More assessment centres to reduce delays."* • *"Assessment of adolescent and adults."* • *"Everything needs improvement as in the other countries I know, including what works well, given that nothing is effective enough to efficiently treat autism and its consequences, particularly its most impairing forms."*
England	• *"Child diagnosis assessment is often working well."* • *"Within my previous NHS job, we had a good MDT for diagnosis thorough assessment process to gain diagnosis".* • *"Good services exist for those with severe autism but those with borderline difficulties struggle a lot."* • *"Assessment and diagnosis of children is very good; also, educational support is good."*	• *"Education, employment assessment and supports, and adult diagnostic assessment pathways."* • *"Timescales for diagnosis and need consistent and prompt therapy following diagnosis, including ABA which is not widely provided under statutory services."* • *"Information available to parents about therapies and approaches available that have a good evidence base post diagnosis."* • *"Clearer training for staff in schools about how to teach skills and improve behaviours proactively rather than reactively."* • *"Post assessment specialist therapy services are needed for children. Practitioners working in adult care and in adult mental health services have a very poor understanding of autism and how it presents in adults; they are often mis diagnosed with personality disorders."*
Italy	• *"Increasing parent awareness, Specialised teams within the National Health system, but with significant differences at the local (regional) level."* • *"Services for cohousing and working are increasing in quantity and quality; there are few specialised centres with unequal distribution. In a few specialized centres assessment is of high quality and also definition of a life project for the subjects is well conducted."*	• *"Make care homogenous at national level health organization, implementing specialized teams within the national health system."* • *"Faster diagnosis, more personalized post-assessment services (not only for person, but for family too), more specialised centres, more effective interventions financed by the Government."* • *"More specialized centres are needed, and free educational support."*

13. Discussion

This study demonstrates that autism is associated with a significant socioeconomic impact generated by the high direct and indirect costs, the increased social isolation and discrimination and the poor QoL and social life outcomes exhibited by autistic individuals and their supporters. Given that autism lasts over an individual's lifetime, the costs due to productivity losses both for the individuals themselves and for their supporters are overwhelmingly high, with significant implications for both the financial and physical wellbeing of autistic individuals and their families. There is a clear deterioration in the health outcomes of autistic people and their supporters in comparison to the rest of the population, with impact increasing in line with autism severity and presence of mental health related concurrent conditions, particularly depression and anxiety. In addition, this study reveals that access to support mechanisms and interventional therapies for autism is limited, or that support services and interventional therapies for autism are accessible but inefficient, which further aggravates the socioeconomic challenges associated with autism. The primary data analysis from this study expands previous knowledge on the experiences, socioeconomic impact, and the QoL of autistic individuals and their supporters across countries. Primary and secondary research results confirm an urgent need to enhance diagnostic processes and support mechanisms in autism, and ultimately achieve better physical/mental health and employment outcomes for autistic individuals and their families.

13.1. Determinants of the burden experienced by autistic individuals

Diagnostic process

Our study revealed a late-age diagnosis at an average of 27 years. This could be explained by the fact that many autistic people experience largely invisible disabilities and therefore may either have been previously misdiagnosed or may have "slipped through the system" without a diagnosis during childhood and may later be diagnosed in adulthood (CASDA Board of Directors, 2019). Additionally, the well documented ability of females to better mask the traits associated with autism when compared to men, often means females are referred for a diagnosis and/or receive a diagnosis later in life. Therefore, the older average age of diagnosis observed in our study could also be attributed to the larger group of female participants in our study sample.

Furthermore, the UK study sample which comprised more than half of our overall study sample, exhibited the oldest mean age of diagnosis compared to other study countries, potentially influencing the older average age of diagnosis observed in our study. Specifically in the UK, an increase in adulthood diagnoses has been reported recently and this has been linked to a growing demand for assessment among adults arising from greater public awareness of autism, and to significant cuts and wait times in children's diagnostic assessment services (Russell et al., 2022). Indeed, our findings demonstrated an average gap of seven years between the first features of autism becoming apparent and the receipt of a diagnosis and this matches concerns related to delayed diagnosis and subsequently delayed autism management and support, not only from England and Scotland (Russell et al., 2022; BMA, 2019; NICE, n.d.) but also from Germany (Höfer et al., 2019), and France (Autisme France, 2015). Additional factors that may contribute to diagnostic delays also include the necessity of multiple specialist appointments required to obtain a diagnosis, a lack of standardised referral pathways, and a lack of healthcare professionals specifically trained in the diagnosis of autism (BMA, 2019). In many clinical settings, a comprehensive evaluation includes multiple appointments with an MDT comprising a physician, psychologist, speech and language therapist, and often other professionals, such as a social worker, occupational therapist, and/or genetic counsellor (Gordon-Lipkin, Foster, & Peacock, 2016). These assessments are time consuming and often need to be funded privately, deterring people from seeking diagnosis. Additionally, professionals who are typically involved in autism diagnosis and treatment generally report receiving very limited training in autism during their qualifying period (Keenan et al., 2015), with similar findings for GPs, who report unfamiliarity with autism in both children and adults (Kornblau, 2014). This latter observation is particularly important given that our survey findings suggest that nearly a third of autistic individuals or their parents raise concerns around the first features of autism with a GP or family doctor. It is also important to highlight that, according to clinicians participating in this study, despite the availability of diagnostic guidelines for autism, there are limited incentives in place for clinicians to follow these guidelines and as a result there is limited adherence, further adding to diagnostic delays.

Moreover, autistic individuals (i.e., adults or parents of autistic children) in our study reported poor satisfaction with their diagnostic process, primarily due to "the time it took to get a diagnosis" and "difficulties involved with finding a professional to help or diagnose". Literature has recognised that autistic adults experience unique autism-specific barriers to healthcare access that may be less likely to be addressed in modern healthcare systems (Wang, Mandell, Lawer, Cidav, & Leslie, 2013). For example, difficulties experienced by autistic people getting to specialist appointments due to the stress and emotional exhaustion associated with arranging and attending doctors' appointments have been raised as a contributor to diagnostic delays for autism in Germany (Höfer et al., 2019), France (Autisme France, 2015) and USA (Joshi et al., 2013). In addition, using the very often crowded methods of public transport to travel to these appointments might represent an additional, significant source of anxiety for these individuals, or a potential contributor to the increased out-of-pocket expenses associated with attending doctors' appointments due to the need for using private transportation. These shortcomings exacerbate the already high rates of missed appointments amongst autistic individuals (Joshi et al., 2013) and more importantly, highlight priority areas within the diagnostic process which should be addressed in order to promote better outcomes in the diagnostic experience among autistic individual populations.

Finally, the most common concurrent conditions in autistic individuals in our survey were anxiety and depression. This is reflected in the literature whereby the most commonly reported reasons for referrals in more than half of autistic adults are impaired mood dysregulation and anxiety (Joshi et al., 2013). As such, the development of specific training and/or guidelines for referrals exhibiting distinct forms and/or combinations of these concurrent conditions could facilitate more accurate and timely diagnoses in individuals with suspected autism.

Quality of Life

Our findings demonstrate that QoL in autistic individuals was negatively affected primarily due to increased anxiety and depression, loneliness/difficulty maintaining relationships and difficulties in social interactions/communications, with respondents exhibiting better overall outcomes on their physical compared to mental health. Other studies have also suggested that QoL in autistic individuals is consistently impaired by the existence and severity of mental health conditions and social-communication difficulties (Oakley et al., 2021). As such, improved outcomes in the QoL of autistic adults call for improved access to effective mental health interventions, and informal and formal support for their social difficulties (Mason et al., 2018).

Furthermore, there are also several factors positively predicting QoL. In this study, these primarily included fulfilment from special abilities and creativity, receiving help and assistance from others and providing help to others. Similarly, literature has demonstrated that receiving support, being employed and in a relationship (Mason et al., 2018), as well as a sense of achievement in autistic children (Oakley et al., 2021), can all act as positive predictors of QoL outcomes. These results highlight potential targets for interventions and services to improve QoL for autistic people (Mason et al., 2018), while showing that placing an emphasis on strengthening performance in these domains can have a profound, positive impact on the overall wellbeing of autistic individuals.

Healthcare costs & social services support

Survey responses showed that average annual out-of-pocket expenses amounted up to just over €16,000 per autistic individual across all study countries and as much as €35,000 when looking solely at the USA. These costs were predominantly generated by expenses on childcare, support worker/personal assistant and privately funded therapy. Participating clinicians confirmed that significant out-of-pocket costs may arise from privately funded interventional therapies and from the need to seek privately funded specialist education and diagnostic services. Other sources have suggested that about 65% of the direct healthcare costs may arise from the support services provided in autism and other, related family expenditure (Prado, 2012). Despite the high out-of-pocket figures exhibited by our survey participants across all countries, up to 70% of them did not receive any state or health insurance funded financial support as a result of their autism, highlighting that improved provision of state financial support could help to significantly reduce at least some of the financial pressure arising in autism from out-of-pocket expenses.

Literature also highlights room for improvement exists in the provision of enhanced and more timely access to social care and support (Fataliyeva, 2020; Keenan et al., 2015), which could help curb expenses generated from seeking privately funded therapies and care. As reported by participating clinicians, government funded support schemes and services for autistic individuals and their supporters do exist, although the geographic distribution of specialist services may be insufficient. Additionally, publicly funded schemes and services are associated with long waiting lists, bureaucracies and lack of adequately trained practitioners to deliver them (C. Anderson et al., 2018). Regional regulations might also result in limited autism related services or diagnostic services further adding to waiting times and deterring individuals from seeking state funded care (Keenan et al., 2015). Furthermore, the fact that one of the key reasons for not receiving financial support was "not applying due to the belief of being ineligible" underscores the need for diagnostic and assessment centers to provide adequate information to autistic individuals and their families about their social security options for funding support and coverage eligibility.

Finally, this study demonstrates that social support in finding appropriate accommodation for adult autistic individuals is not widely available. This has implications for a large proportion of our adult respondents who reported that despite still living with family they aim to live more independently than they currently do. Improved state funded services on supported living and innovative housing solutions are essential to enable autistic people to have control over their living arrangements and accommodation and hence, achieve a greater sense of independent living (Global News, 2020).

Therapy after diagnosis

Results from our survey indicate that, despite almost 40% of autistic individuals not using any medication specifically for autism, a significant proportion of prescribed medication in autism still arises from the use of antidepressant, anxiolytic, and antipsychotic medication to manage mental health associated characteristics of autism.

Most participating clinicians expressed a concern around over-medication of autistic individuals, while confirming that over-prescribing in autism arises predominantly from the use of antipsychotic and antidepressant therapy. Findings from the literature also suggest that mental health related comorbidities concurrent conditions are highly associated with increased drug utilisation, reportedly leading to a 50% increase in psychotropic drug use (Gotham et al., 2015; Khanna, Jariwala, & West-Strum, 2013b). It follows that alternative management of mental health related concurrent conditions through interventional therapies might drastically reduce the rate of prescribed medication in autism, with immediate implications towards reducing both the overprescribing burden for health systems and the burden arising for individuals due to out-of-pocket expenses and side-effects associated with long-term use of these drugs.

Most autistic individuals in our survey did not receive any behavioural or psychological therapies or interventions for their autism and of those who received such therapies, a quarter reported that these made “no difference”. More importantly, despite CBT and SSGs being the therapies most often rated by autistic individuals in our study as making “no difference”, these were also the most frequently used interventions by clinicians in our study. This observation, coupled with the significant utilisation rate of psychotropic drugs among our study sample, underscores the possibility of providing more efficient interventional therapies by following a more individualised approach, where suitable and desirable, targeting each individual’s needs for managing their specific autism associated mental health characteristics.

More broadly, the above highlights the importance of ensuring that interventions are targeted such that they facilitate meaningful changes in the behaviour of and outcomes for the autistic individual (Keenan et al., 2015). In addition, clinicians' responses on the utilisation of interventional therapies in autism demonstrate an urgent need not only to increase healthcare coverage for these interventions but most importantly to focus on improving the availability of trained practitioners and reducing waiting times for accessing these services. Of course, the relatively low number of CBT and SSG sessions received by individuals in our study compared to VBT or RDI sessions, combined with the long wait times experienced from referral to actual utilisation of these therapies could have also influenced individuals' perception of the benefit they acquired from these interventions.

Finally, our results underscore a remaining and growing need to explore novel autism management approaches that will offer drastic changes for autistic individuals and their families, while improving the outcomes of current practices and interventions. Currently, there are many pharmacological and behavioural interventions to improve outcomes by alleviating symptoms in autism but none of these truly address the key aspects of autism that impair autistic individuals' QoL and wellbeing, including issues with social engagement, isolation and repetitive behaviours (Miller, 2021). Additionally, research and evidence generation on the added benefit of many of the current modalities in autism management is limited (Medavarapu et al., 2019). A few novel approaches in the management of autism have been discussed recently, although these remain under investigation.

In terms of diagnostics, one of the latest approaches discussed in the literature relates to identifying behavioural and neurobiological markers indicative of a very high likelihood of developing autism as early as 6 months of age; this offers a novel opportunity to optimise functional outcomes by intervening during a potentially more sensitive timeframe compared to current practices of intervening early after diagnosis (Grzadzinski et al., 2020). Furthermore, in terms of pharmacological innovations, Suramin, an investigational, antipurinergic drug has achieved significant and steady improvement in several efficacy assessment measures during its Phase II trial and hence, has gained traction as a promising treatment for the core symptoms of autism through the reduction of neuroinflammation (Begley, 2021). Finally, in terms of behavioural interventions, a novel approach that has been discussed but is still under investigation relates to virtual reality-social cognition training, which delivered promising results in terms of meaningful neurological and behavioural changes that improve social and emotional processing among autistic individuals (Yang et al., 2018).

Despite progress in pharmacological innovations, exploring new pathways for prevention and intervention in autism remains a key approach to improve trajectories in QoL, social interaction and supporter outcomes. On that front, future innovations in autism research will require multidisciplinary, collaborative action between diagnostics, neuroimaging, and intervention science to unravel the primary mechanisms behind the emergence of autism and develop the respective personalized interventions to target these mechanisms (Brian et al., 2016).

Education

According to our survey, across all levels of education (excluding special education), and particularly in secondary schools the majority of respondents reported that their respective educational institutions did not meet their needs at all. Poor satisfaction with the educational environment and standards for autistic individuals primarily arose due to high rates of discrimination experienced by these individuals, particularly in secondary school and by female individuals. Literature has also associated the presence of autism in children with a greater risk of being bullied, particularly for children in full inclusion classrooms as opposed to those who spend the majority of their time in special education settings (Zablotsky, Bradshaw, Anderson, & Law, 2014). Despite the willingness of governments to support those with disabilities and special requirements, many participating clinicians report that public special education institutions or programs are often not available due to local funding restrictions. Therefore, access to special education for autistic individuals may be completely restricted, particularly for individuals whose families are not in a position to privately fund enrolment in private special needs schools (Angloinfo, n.d.). Additionally, participating clinicians in our study have linked delayed diagnosis and assessment in autism with subsequent negative implications in the educational pathway of autistic individuals. This is in part reflected by the poor educational support experienced among our study participants whose average age when first features of autism were noticed and when diagnosis was made were both in adulthood. The late-age diagnosis observed in our sample also indicates that a large group of respondents were not aware of their autism while attending primary and secondary school. Thus, by definition, their respective educational outcomes could be worse compared to those that would have been observed among a cohort of individuals aware of their autism during childhood.

Furthermore, given that autism awareness amongst younger children is considerably lower compared to adults and that those who are aware of autism features tend to be more accepting of those who present with autism-related requirements (Dillenburger, Jordan, McKerr, Lloyd, & Schubotz, 2017), it is important to introduce autism awareness activities, particularly in the primary and secondary education settings. Finally, improved educational outcomes in autism also call for improved training and support for teachers of autistic individuals. High school teachers and health care professionals report a lack of support from their respective institutions to enhance their knowledge of autism, while the need for clearer autism training for educational staff is also raised by clinicians participating in our study. The literature highlights that more comprehensive autism training for educational staff can in turn help improve the transition experiences of autistic young adults (K. A. Anderson, Sosnowy, Kuo, & Shattuck, 2018b).

Employment

Findings from our survey demonstrated that only about 40% of the autistic individuals asked are working either full- or part-time or are self-employed. Employment rates in autistic people are not significantly higher than 50% (Vogeley et al., 2013). Those with late-life diagnosis of autism are at a particular disadvantage participating in the labour market (Frank et al., 2018). As well as struggling to maintain professional positions that are suited to their formal qualifications, high unemployment rates among autistic individuals further lead to social isolation, low self-esteem, and other concurrent conditions, including depression and anxiety (Vogeley et al., 2013). Factors that hinder employment opportunities for these individuals include the presence of mental health related concurrent conditions, linguistic capabilities, and the presence of maladaptive behaviours and social impairments (Ohl et al., 2017). Participating clinicians’ views also demonstrated the significance of delayed diagnosis and assessment in autism in terms of a negative employment outlook for autistic individuals. Nevertheless, factors external to the autistic individual, such as negative social views about autism, are also believed to contribute to employers’ underestimation of the capabilities of autistic employees, further contributing to unemployment issues (K. A. Anderson et al., 2018b). Our survey demonstrated that a lack of understanding about autism in the workplace, and a lack of support and social interaction in the workplace, including issues related to non-autistic colleagues being unable or unwilling to accept autistic individuals’ needs, are among the key aspects that have a negative impact on the working life of autistic people. One of the key suggestions from survey participants in order to make employment easier was work to increase the awareness and understanding among colleagues about the unique features and requirements of autistic individuals.

13.2. Determinants of the burden experienced by supporters of autistic individuals

Results from the survey for supporters of autistic individuals demonstrate that the majority of supporters miss an average of eight working days per month due to their caregiving responsibilities. Indeed, parents, and almost exclusively mothers (Cidav et al., 2012; Prado, 2012; Vaincre L'Autisme, 2013), raising an autistic child significantly sacrifice their career in order to ensure their child is provided with the medical and educational support required (Zablotsky et al., 2013). As a result, parents of autistic children endure substantial financial strain arising not only from out-of-pocket expenses related to therapies, special education, childcare, and additional support services, but primarily also from decreased workforce involvement (Lavelle et al., 2014), which can reportedly lead to a decrease of about 30% in family earnings compared to families of children with no disabilities (Ghanizadeh, Alishahi, & Ashkani, 2009).

The employment related burden is further escalated by the limited support provided for these families. For example, in our survey, 41% of employed supporters felt that their current, or most recent, employer did not provide sufficient support in light of the fact that they care for an autistic child. Additionally, about 60% reported that they have not received any financial support from the government for taking care of an autistic person. Of course, a family's financial status also significantly affects overall QoL outcomes (Cappe et al., 2018). Nevertheless, it is important to highlight that nearly 15% of supporters, reported that receiving financial support would not offer a significant improvement in their life as a supporter, despite most of them not being in full-time paid employment. This underscores the interconnected impact of other determinants of supporter burden, such as emotional QoL, on the overall wellbeing of autistic individuals' supporters. Both our study and the relevant literature demonstrate that significant challenges for supporters of autistic individuals arise from mental health issues, including increased stress and depression rates (Cohrs & Leslie, 2017; Craig et al., 2016; Dudley & Emery, n.d.; Herrema et al., 2017), social exclusion and isolation (Marsack & Samuel, 2017), poor sleep patterns (Johnson et al., 2018) and less engaged, balanced, and cooperative relationship with their partner or spouse (Hartley et al., 2017). Additionally, many of the poor outcomes that supporters of autistic individuals experience arise from the specific emotional burden (Rattaz et al., 2017) related to constant feelings of fear about the future of the person they care for or the feeling that the person they care for is dependent on them. Therefore, the type of support that would address some of the challenges experienced by supporters of autistic individuals primarily relates to the provision of family, emotional, and educational support. For example through marriage and psychological counselling that aims to acknowledge their experiences and direct them to resources to help them overcome the challenges they face with autism (Frye, 2016) and through educational support to understand features of autism and the needs related to the social development of the autistic child or adolescent (Hartley & Schultz, 2015).

The above also highlights the need to incorporate informal supporters' perspectives in assessing the value of interventions in autism. Despite significant progress on the development of novel interventions for the management of autism, quantifying the progress and the value brought by these interventions for autistic individuals and their families/supporters remains a challenge (Grzadzinski et al., 2020; McConachie et al., 2018).

Currently available evaluation measures include standardised assessments such as supporter and clinician ratings of adaptive functioning and treatment response (Grzadzinski et al., 2020), which often lack the sensitivity to capture more subtle changes observed as a result of an intervention (Bacon et al., 2014). The evaluation of interventions for autism is further hampered by the multitude of outcomes to be measured. Therefore, collaboration between clinicians, allied healthcare professionals and supporters of autistic individuals arises as a priority in autism relevant research, to develop a core set of outcome measures that capture the added value of interventions in greater specificity and granularity (McConachie et al., 2018). Furthermore, supporter engagement and participation in research is essential to ensure that the outcomes measured are important to and appropriate not only for autistic individuals but also for the supporters of these individuals. Given the well-documented supporter strain in autism, measuring outcomes that are valued by families and/or informal supporters is paramount to identify the interventions that are most effective in alleviating this burden. Ultimately, this can help to determine the interventions and support services that should be prioritised for evaluation research (McConachie et al., 2018).

14. Policy implications & recommendations

Our results, coupled with existing findings from the literature confirm that there is an urgent need to achieve better outcomes for autistic people and their supporters. Evidence suggests that this is possible if policy makers address a series of issues to secure the following goals:

1. *Shift the paradigm in autism management towards provision of earlier assessment and diagnosis.*

The focus of clinical care in autism should shift from symptom management to a paradigm of maximizing human potential by providing early life or childhood diagnosis. Earlier diagnosis is paramount to maximize future employment capacity for autistic people and hence, achieving a greater level of independent living and improved QoL outcomes. Towards this goal it is imperative that healthcare systems:

- Ensure wider coverage of diagnostic services and evaluations in cases of where autism is suspected. Often, high-cost diagnostic services in autism need to be funded privately, leading to a high rate of foregone appointments. Therefore, providing greater coverage for diagnostic assessments in suspected autism cases, both for children and adults, could encourage more timely diagnostic outcomes in autism.
- Minimize the number of visits required for diagnostic assessments to avoid diagnostic delays. The plethora of healthcare professionals involved in autism diagnosis, and the respective multiple visits required for assessments often deters individuals from seeking diagnostic services due to the stress and emotional exhaustion associated with arranging and attending doctors' appointments.
- Raise awareness among healthcare professionals and appointment coordinators about the sensory and emotional challenges that doctors' offices present for autistic people and about the need to accommodate visits accordingly to avoid missed or postponed appointments.

2. *Tailor interventions and behavioural support mechanisms based on a person-centred approach that addresses the personalised needs of autistic individuals and their supporters.*

The wide range of autism manifestations in individuals and their personal circumstances highlights that diagnosis, treatment and management goals should be person-specific to provide the best health outcome according to the specific physical, social, and behavioural needs of every autistic individual. To achieve this, interventional therapies, and behavioural support in autism should:

- Focus on strengthening individuals' performance in domains that have a positive impact on their QoL outlook, such as encouraging individuals' special abilities & creative skills and rewarding achievements, particularly in autistic children.
- Prioritise the management of mental health related concurrent conditions which are often present for many autistic individuals. Managing mental health related concurrent conditions through targeted interventional therapies can help reduce overprescribing and overspending arising from the increased use of psychotropic medication in autism and prevent side-effects associated with long-term use of these drugs.

3. *Re-define the priorities of social support mechanisms, while enhancing the availability and quality of existing schemes.*

Support mechanisms should focus on achieving independent living and meaningful participation in society for autistic individuals. More precisely, these should aim to:

- Enable people to have control over their lives, education, and accommodation/living arrangements, through supported living and innovative housing solutions, support services for autistic children to direct them in deciding which education pathway they should follow.
- Encourage activities that are centered around autistic individuals' participation in, and contribution to, the local community.

Wider and more timely access to social care and support is a key step towards establishing affordable autism care services for everyone and minimizing the need to seek privately funded care. To achieve this goal, policy makers should:

- Ensure that state-funded day services provide both timely and quality care and support, through adequately trained people, while also being readily accessible both in terms of geographic location and regional access regulations or bureaucracies.
- Secure local funding and accessibility/availability of: i) public special education institutions or programs and social policies, ii) personalised support measures for autistic pupils whether in mainstream or special education and iii) practice guidelines to guide the implementation of systems for young autistic people, transitioning from school or college to adulthood.

- Ensure that diagnostic and assessment centers provide adequate and accurate information to autistic individuals and their families about their social security options for funding support and coverage eligibility.

Given that significant impairment in QoL outcomes arises due to mental health related concurrent conditions often present among autistic people, improved outcomes in the wellbeing of these individuals call for improved access to effective mental health interventions, and informal and formal support for their social difficulties.

4. *Restructure autism specific training and guidelines for clinicians to improve the diagnostic and clinical care outcomes for autistic individuals.*

    - Set out incentivisation mechanisms for clinicians to follow autism diagnostic guidelines across healthcare systems to improve diagnostic pathways and the quality of clinical care provided in autism.
    - Increased responsiveness of health care systems and adaptation of guidelines to the most updated evidence on autism is essential for improved diagnostic outcomes but also for strengthening interventions and monitoring practices in autism management and hence, avoiding inappropriate over-prescribing for autistic individuals.
    - Establish adult and gender-specific diagnostic protocols in routine clinical practice. These should reflect the distinct age and gender-specific characteristics which may mimic or mask autism related features and which, if misinterpreted or unrecognised, may lead to inaccurate, missed, or delayed diagnoses.
    - Implement specific training and referral guidelines for cases with distinct forms of and/or combination of impaired mood dysregulation and anxiety to facilitate accurate and timely diagnoses in individuals with suspected autism.

5. *Educate society, schools, and workplaces on the requirements of autistic individuals and involve these entities in collaboratively achieving better outcomes in autism.*
    - Foster greater awareness and understanding of autism among workplaces and employers to achieve better employment prospects for autistic individuals.
    - Allocate designated mentors or advisors in the workplace to help with disclosing autism diagnosis at work and explaining the individual’s requirements to colleagues (with permission). This can strengthen the performance of autistic individuals at work and improve overall employment outcomes in autism.

- Introduce autism awareness activities for young children, particularly in the primary and secondary education setting to help prevent the discrimination currently experienced by autistic children within the educational environment.
- Improved training and support for teachers of autistic children and adolescents is also essential for the improvement of educational outcomes in autism.
- Collaboration between the educational, workplace and social care sectors is essential to form integrated transition pathways for autistic children/adolescents, to support smooth transition to adulthood. Transition planning activities should cover all areas of service provision, including housing and employment support.

6. *Measure meaningful outcomes and generate further robust evidence to inform decision making in the management of autism.*

The prevalence of autism has been rising over the last decade, but this has not been accompanied by respectively rigorous monitoring of clinical outcomes in autism. Therefore, the following arise as priority areas for autism policy relevant research:

- Perform studies based on real world data with the support of national registries to measure the benefit of early diagnosis and hence, early intervention on the long-term outcomes for autistic individuals and their families. This is important because despite the suggested benefit of early diagnosis on the long-term prognosis in autism there is as yet no quantifiable evidence of this benefit.
- Measure and evaluate health outcomes on domains that matter the most for autistic individuals and their supporters. For autistic individuals, these should focus on measuring outcomes on mental health state and satisfaction with social interactions and relationships and for supporters, outcomes on their emotional health and social life status. However, given the large heterogeneity of autism manifestations and characteristics among the autism community, the above aspects should be adapted and measured in the context of a more personalised outcomes measurement approach for each individual.
- Multi-stakeholder engagement and collaboration in autism relevant evaluation research is critical to ensure measurement of meaningful outcomes in autism; involvement of supporters is specifically important to develop a shared understanding on the various levels of intertwined outcomes that add value both for autistic individuals and their families.

Limitations

The findings and subsequent recommendations presented here should be interpreted with caution, given the inherent methodological limitations posed by a web-survey based analysis. Firstly, the uneven geographical spread of the respondents, notably the larger cohort from the UK, could have an impact on our findings – specifically those around the age of diagnosis and gender prevalence, given the increased incidence of adult, female diagnoses in the UK. The older age of participants could have also influenced findings in the education section, as an older average age of participants may mean that responses are not reflective of the current or recent schooling and support standards in place across the study countries.

Secondly, the use of a web-survey allowed for potentially misinterpreted questions by respondents, an inability to validate respondents' understanding/interpretation of the questionnaire items, and self-reported data based on each clinician's, autistic individual's and/or supporter's level of knowledge and experience on the specific indicator in question. Similarly, as nearly 40% of responses were from supporters on behalf of autistic individuals it is crucial to highlight that we cannot assess the supporters' level of understanding or accuracy of the responses provided.

Thirdly, we have measured the level of verbal communication ability as a proxy for the 'severity' of autism and given that most respondents had no or some problem communicating verbally, we have not necessarily captured the different experiences, costs and burden exhibited between individuals with different levels of autism severity. Therefore, the results presented in this report cannot be viewed as entirely representative of the true environment and practices followed in autism care within the study countries or the true outcomes observed in a largely heterogeneous international population of autistic individuals.

Finally, there are also limitations from distributing the patient survey via reddit. By sharing the survey through online forums, we were able to reach a population that may not otherwise be represented in the literature. However, by not distributing the survey through established patient organisations, there is a risk of reaching individuals who have not been officially diagnosed. To combat this risk, it was clearly communicated when sharing the survey that only autistic individuals 18 or over, autistic individuals under 18 accompanied by someone aged 18 or over, and individuals over 18 who care for autistic individuals of any age were eligible to complete the survey. Additionally, it was clearly noted that self-diagnosed individuals were not eligible for participation. Of course, as researchers cannot access patient information, it is not feasible to confirm that every survey participant met these criteria.

15. Conclusion

Our results, combined with existing findings from the literature, provide a strong evidence base for the unmet need currently present in the management of autism. Inefficiencies in the diagnostic processes and interventional therapies, poor employment prospects and the inability to live independently represent a substantial and growing challenge for some autistic individuals. Additionally, the increased emotional stress and productivity losses exhibited by the supporters of these individuals further contributes to the broader socioeconomic implications of autism. A fundamental step towards improved long-term outcomes in autism is the provision of early diagnosis and assessment. This could maximise future employment capacity for autistic individuals and curb a significant proportion of socioeconomic costs associated with lost employment opportunities and the linked mental and social health implications for autistic individuals. Nevertheless, further evidence from pragmatic studies based on data from national registries is needed to quantify the magnitude of this benefit for autistic individuals, their families, and society overall.

Additionally, governments and healthcare systems should centre their efforts specifically on adapting infrastructure, training, and clinical guidelines such that they can support clinicians in optimising diagnostic and referral pathways, and clinical management in autism, including the ability to measure and evaluate meaningful QoL and outcomes-relevant data in an automated, systematic way. Funding efficient, person-specific interventions is also essential to provide the best health outcome according to the specific physical, social, and behavioural needs of every autistic individual. Finally, global, co-ordinated political action and cross-border collaboration is also needed to educate societies, schools, and workplaces about the requirements of autistic individuals. The effective collaboration of these sectors is paramount for the smooth transitioning of autistic children and adolescents to adulthood, including better living arrangements and employment options and achieving a sense of meaningful participation in society for every autistic individual.

The policy recommendations arising from this study highlight that improved outcomes in autism are feasible if policy makers address the key determinants of burden, as identified in our study, for autistic individuals and their families. Of course, as our study was conducted in the early stages of the COVID-19 pandemic, it does not necessarily capture any additional burden arising from COVID-19 for autistic individuals and their families and therefore, more recent, real-world evidence is essential to elucidate the full social and economic impact of autism across countries as it is currently shaped in a post-pandemic environment.

References

Anderson, C., Lupfer, A., & Shattuck, P. T. (2018). Barriers to Receipt of Services for Young Adults With Autism. *Pediatrics*, *141*(Supplement 4), S300--S305. https://doi.org/10.1542/peds.2016-4300G

Anderson, K. A., Sosnowy, C., Kuo, A. A., & Shattuck, P. T. (2018a). Transition of Individuals With Autism to Adulthood: A Review of Qualitative Studies. *Pediatrics*, *141*(Suppl 4), S318–S327. https://doi.org/10.1542/peds.2016-4300I

Anderson, K. A., Sosnowy, C., Kuo, A. A., & Shattuck, P. T. (2018b). Transition of Individuals With Autism to Adulthood: A Review of Qualitative Studies. *Pediatrics*, *141*(Suppl 4), S318–S327. https://doi.org/10.1542/peds.2016-4300I

Angloinfo. (n.d.). Special Needs Education in Canada . Retrieved April 26, 2021, from https://www.angloinfo.com/how-to/canada/family/schooling-education/special-needs-education

ASDEU. (2018). *Autism Spectrum Disorders in the European Union* . Retrieved from http://asdeu.eu

Autism Canada, Autism Research Institute, & Pacific Autism Family Network. (2017). *Aging And Autism: A Think Tank Round Table*. Ontario.

Autism Nova Scotia. (2015). *Investing in Nova Scotians Living with Autism : A Collaborative Framework Approach to Building Sustainable Supports and Services Across the Lifespan*.

Autisme France. (2015). *Alternative Report by the Association 'Autisme France' addressed to the Committee for Human Rights in the context of HRC's review of France's fifth periodical report.* Paris.

Autistica. (n.d.). *Personal tragedies, public crisis The urgent need for a national response to early death in autism*.

Avis, L., & Prado, C. (2012). *Les éditions des JOURNAUX OFFICIELS Le coût économique et social de l'autisme*.

Bacon, E. C., Dufek, S., Schreibman, L., Stahmer, A. C., Pierce, K., & Courchesne, E. (2014). Measuring Outcome in an Early Intervention Program for Toddlers with Autism Spectrum Disorder: Use of a Curriculum-Based Assessment. *Autism Research and Treatment*, *2014*, 1–9. https://doi.org/10.1155/2014/964704

BACP. (2016, September). Adapting CBT for children with an autism spectrum disorder (ASD). Retrieved July 15, 2021, from https://www.bacp.co.uk/bacp-journals/bacp-children-young-people-and-families-journal/september-2016/creative-cbt-with-autism-spectrum-disorder/

Barrett, B., Mosweu, I., Jones, C. R. G., Charman, T., Baird, G., Simonoff, E., … Byford, S. (2015). Comparing service use and costs among adolescents with autism spectrum disorders, special needs and typical development. *Autism*, *19*(5), 562–569. https://doi.org/10.1177/1362361314536626

Begley, A. (2021, October 29). *IV suramin may be a promising autism treatment, shows Phase II study*. https://www.europeanpharmaceuticalreview.com/news/164740/iv-suramin-may-be-a-promising-autism-treatment-shows-phase-ii-study/

BMA. (2019). *Failing a generation: delays in waiting times from referral to diagnostic assessment for autism spectrum disorder*.

BMA. (2020). Autism spectrum disorder. Retrieved February 20, 2021, from BMA website: https://www.bma.org.uk/what-we-do/population-health/child-health/autism-spectrum-disorder

Borgi, M., Ambrosio, V., Cordella, D., Chiarotti, F., & Venerosi, A. (2019). Nationwide

Survey of Healthcare Services for Autism Spectrum Disorders (ASD) in Italy. *Advances in Neurodevelopmental Disorders*, *3*(3), 306–318. https://doi.org/10.1007/s41252-019-00113-1

Brian, J., Doyle-Thomas, K., Baribeau, D., & Anagnostou, E. (2016). Novel mechanisms and treatment approaches in autism spectrum disorder. *Discovery Medicine*, *22*(119), 47–54.

Brookman-Frazee, L., Stadnick, N., Chlebowski, C., Baker-Ericzén, M., & Ganger, W. (2018). Characterizing psychiatric comorbidity in children with autism spectrum disorder receiving publicly funded mental health services. *Autism : The International Journal of Research and Practice*, *22*(8), 938–952. https://doi.org/10.1177/1362361317712650

Buck, T. R., Viskochil, J., Farley, M., Coon, H., McMahon, W. M., Morgan, J., & Bilder, D. A. (2014). Psychiatric comorbidity and medication use in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *44*(12), 3063–3071. https://doi.org/10.1007/s10803-014-2170-2

Buescher, A. V. S., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatrics*, *168*(8), 721–728. https://doi.org/10.1001/jamapediatrics.2014.210

Burgess, S., & Cimera, R. E. (2014). Employment outcomes of transition-aged adults with autism spectrum disorders: a state of the States report. *American Journal on Intellectual and Developmental Disabilities*, *119*(1), 64–83. https://doi.org/10.1352/1944-7558-119.1.64

Byford, S., Cary, M., Barrett, B., Aldred, C. R., Charman, T., Howlin, P., … Green, J. (2015). Cost-effectiveness analysis of a communication-focused therapy for pre-school children with autism: results from a randomised controlled trial. *BMC Psychiatry*, *15*(1), 316. https://doi.org/10.1186/s12888-015-0700-x

Cappe, É., Poirier, N., Sankey, C., Belzil, A., & Dionne, C. (2018). Quality of life of French Canadian parents raising a child with autism spectrum disorder and effects of psychosocial factors. *Quality of Life Research*, *27*(4), 955–967. https://doi.org/10.1007/s11136-017-1757-4

CASDA Board of Directors. (2019). *Better Together: The Case for a Canadian Autism Partnership*.

Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. *The Lancet Psychiatry*, *1*(2), 142–147. https://doi.org/10.1016/S2215-0366(14)70248-2

Center for Disease Control. (2021). *A Snapshot of Autism Spectrum Disorder in 2018. Key Findings from the ADDM Network*. https://www.cdc.gov/ncbddd/autism/addm-community-report/key-findings.html

Center for Disease Control. (2020) CDC estimate on autism prevalence. Retrieved February 20, 2021, from Autism Speaks website: https://www.autismspeaks.org/press-release/cdc-estimate-autism-prevalence-increases-nearly-10-percent-1-54-children-us

Chamak, B., Bonniau, B., Oudaya, L., & Ehrenberg, A. (2011). The autism diagnostic experiences of French parents. *Autism*, *15*(1), 83–97. https://doi.org/10.1177/1362361309354756

Cidav, Z., Marcus, S. C., & Mandell, D. S. (2012). Implications of childhood autism for parental employment and earnings. *Pediatrics*, *129*(4), 617–623. https://doi.org/10.1542/peds.2011-2700

Cohrs, A. C., & Leslie, D. L. (2017). Depression in Parents of Children Diagnosed with Autism Spectrum Disorder: A Claims-Based Analysis. *Journal of Autism and Developmental Disorders*, *47*(5), 1416–1422. https://doi.org/10.1007/s10803-017-3063-y

Craig, F., Operto, F. F., De Giacomo, A., Margari, L., Frolli, A., Conson, M., … Margari, F.

(2016). Parenting stress among parents of children with Neurodevelopmental Disorders. *Psychiatry Research*, *242*, 121–129. https://doi.org/10.1016/j.psychres.2016.05.016

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, *20*(2), 153–162. https://doi.org/10.1177/1362361315573636

Croen, L. A., Najjar, D. V, Ray, G. T., Lotspeich, L., & Bernal, P. (2006). A Comparison of Health Care Utilization and Costs of Children With and Without Autism Spectrum Disorders in a Large Group-Model Health Plan. *Pediatrics*, *118*(4), e1203--e1211. https://doi.org/10.1542/peds.2006-0127

Davignon, M. N., Qian, Y., Massolo, M., & Croen, L. A. (2018). Psychiatric and Medical Conditions in Transition-Aged Individuals With ASD. *Pediatrics*, *141*(Supplement 4), S335 LP-S345. https://doi.org/10.1542/peds.2016-4300K

Dietz, P., Rose, C., McArthur, D., & Maenner, M. (2020). National and State Estimates of Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*. Retrieved from https://www.cdc.gov/ncbddd/autism/features/adults-living-with-autism-spectrum-disorder.html

Dillenburger, K., Jordan, J. A., McKerr, L., Lloyd, K., & Schubotz, D. (2017). Autism awareness in children and young people: surveys of two populations. *Journal of Intellectual Disability Research*, *61*(8), 766–777. https://doi.org/10.1111/jir.12389

Dudley, C., & Emery, J. C. H. (n.d.). *THE VALUE OF CAREGIVER TIME: COSTS OF SUPPORT AND CARE FOR INDIVIDUALS LIVING WITH AUTISM SPECTRUM DISORDER*. Retrieved from www.policyschool.ca

Dudley, C., & Emery, J. C. H. (2014). *THE VALUE OF CAREGIVER TIME: COSTS OF SUPPORT AND CARE FOR INDIVIDUALS LIVING WITH AUTISM SPECTRUM DISORDER*. Retrieved from www.policyschool.ca

Dudley, C., Nicholas, D. B., & Zwicker, J. D. (2015). *WHAT DO WE KNOW ABOUT IMPROVING EMPLOYMENT OUTCOMES FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDER?* Retrieved from www.policyschool.ca

Erasmus +, & TRAIL Project. (2016). *Social Policy-TRAIL: the road with autism to independent living Country Disability Policy Autism-specific Policy*.

Fataliyeva, S. (2020). *Supporting people with autism and their families I. Draft resolution 2 , 3*. Retrieved from http://www.assembly.coe.int/LifeRay/SOC/Pdf/DocsAndDecs/2020/AS-SOC-2020-PV-01-

Frank, F., Jablotschkin, M., Arthen, T., Riedel, A., Fangmeier, T., Hölzel, L. P., & Tebartz van Elst, L. (2018). Education and employment status of adults with autism spectrum disorders in Germany - A cross-sectional-survey. *BMC Psychiatry*, *18*(1). https://doi.org/10.1186/s12888-018-1645-7

Frye, L. (2016). Fathers' Experience With Autism Spectrum Disorder: Nursing Implications. *Journal of Pediatric Health Care : Official Publication of National Association of Pediatric Nurse Associates & Practitioners*, *30*(5), 453–463. https://doi.org/10.1016/j.pedhc.2015.10.012

Fuentes, J., Basurko, A., Isasa, I., Galende, I., Muguerza, M. D., García-Primo, P., … Posada de la Paz, M. (2021). The ASDEU autism prevalence study in northern Spain. *European Child and Adolescent Psychiatry*, *30*(4), 579–589. https://doi.org/10.1007/s00787-020-01539-y

Ganz, M. L. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics & Adolescent Medicine*, *161*(4), 343–349. https://doi.org/10.1001/archpedi.161.4.343

Ghanizadeh, A., Alishahi, M.-J., & Ashkani, H. (2009). Helping families for caring children with autistic spectrum disorders. *Archives of Iranian Medicine*, *12*(5), 478–482.

Giarelli, E., Ruttenberg, J., & Segal, A. (2013). Bridges and barriers to successful transitioning as perceived by adolescents and young adults with asperger syndrome. *Journal of Pediatric Nursing*, *28*(6), 563–574. https://doi.org/10.1016/j.pedn.2012.12.010

Global News. (2020). CANADA: The struggle faced by Canadian adults with autism. Retrieved April 26, 2021, from https://www.timminstoday.com/local-news/canada-the-struggle-faced-by-canadian-adults-with-autism-2101452

Gordon-Lipkin, E., Foster, J., & Peacock, G. (2016, October 1). Whittling Down the Wait Time: Exploring Models to Minimize the Delay from Initial Concern to Diagnosis and Treatment of Autism Spectrum Disorder. *Pediatric Clinics of North America*, Vol. 63, pp. 851–859. https://doi.org/10.1016/j.pcl.2016.06.007

Gotham, K., Marvin, A. R., Taylor, J. L., Warren, Z., Anderson, C. M., Law, P. A., … Lipkin, P. H. (2015). Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network data. *Autism*, *19*(7), 794–804. https://doi.org/10.1177/1362361315583818

Government of Canada. (2018). Autism Spectrum Disorder among Children and Youth in Canada. Retrieved February 20, 2021, from Government of Canada website: https://www.canada.ca/en/public-health/services/publications/diseases-conditions/infographic-autism-spectrum-disorder-children-youth-canada-2018.html

Grzadzinski, R., Janvier, D., & Kim, S. H. (2020). Recent Developments in Treatment Outcome Measures for Young Children With Autism Spectrum Disorder (ASD). *Seminars in Pediatric Neurology*, *34*, 100806. https://doi.org/10.1016/j.spen.2020.100806

Halladay, A. K., Bishop, S., Constantino, J. N., Daniels, A. M., Koenig, K., Palmer, K., … Szatmari, P. (2015). Sex and gender differences in autism spectrum disorder: Summarizing evidence gaps and identifying emerging areas of priority. *Molecular Autism*, *6*(1). https://doi.org/10.1186/s13229-015-0019-y

Hand, B. N., Lane, A. E., De Boeck, P., Basso, D. M., Nichols-Larsen, D. S., & Darragh, A. R. (2018). Caregiver Burden Varies by Sensory Subtypes and Sensory Dimension Scores of Children with Autism. *Journal of Autism and Developmental Disorders*, *48*(4), 1133–1146. https://doi.org/10.1007/s10803-017-3348-1

Hartley, S. L., Papp, L. M., Mihaila, I., Bussanich, P. M., Goetz, G., & Hickey, E. J. (2017). Couple Conflict in Parents of Children with versus without Autism: Self-Reported and Observed Findings. *Journal of Child and Family Studies*, *26*(8), 2152–2165. https://doi.org/10.1007/s10826-017-0737-1

Hartley, S. L., & Schultz, H. M. (2015). Support needs of fathers and mothers of children and adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *45*(6), 1636–1648. https://doi.org/10.1007/s10803-014-2318-0

Herrema, R., Garland, D., Osborne, M., Freeston, M., Honey, E., & Rodgers, J. (2017). Mental Wellbeing of Family Members of Autistic Adults. *Journal of Autism and Developmental Disorders*, *47*(11), 3589–3599. https://doi.org/10.1007/s10803-017-3269-z

Höfer, J., Hoffmann, F., Dörks, M., Kamp-Becker, I., Küpper, C., Poustka, L., … Bachmann, C. J. (2021). Health Services Use and Costs in Individuals with Autism Spectrum Disorder in Germany: Results from a Survey in ASD Outpatient Clinics. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-021-04955-4

Höfer, J., Hoffmann, F., Kamp-Becker, I., Poustka, L., Roessner, V., Stroth, S., … Bachmann, C. J. (2019). Pathways to a diagnosis of autism spectrum disorder in Germany: A survey of parents. *Child and Adolescent Psychiatry and Mental Health*, *13*(1), 16. https://doi.org/10.1186/s13034-019-0276-1

Houghton, R., Ong, R. C., & Bolognani, F. (2017). Psychiatric comorbidities and use of psychotropic medications in people with autism spectrum disorder in the United States. *Autism Research*, *10*(12), 2037–2047. https://doi.org/https://doi.org/10.1002/aur.1848

Järbrink, K., McCrone, P., Fombonne, E., Zandén, H., & Knapp, M. (2007). Cost-impact of young adults with high-functioning autistic spectrum disorder. *Research in Developmental Disabilities*, *28*(1), 94–104. https://doi.org/10.1016/j.ridd.2005.11.002

Johnson, C. R., Smith, T., DeMand, A., Lecavalier, L., Evans, V., Gurka, M., … Scahill, L. (2018). Exploring sleep quality of young children with autism spectrum disorder and disruptive behaviors. *Sleep Medicine*, *44*, 61–66. https://doi.org/10.1016/j.sleep.2018.01.008

Joshi, G., Wozniak, J., Petty, C., Martelon, M. K., Fried, R., Bolfek, A., … Biederman, J. (2013). Psychiatric Comorbidity and Functioning in a Clinically Referred Population of Adults with Autism Spectrum Disorders: A Comparative Study. *Journal of Autism and Developmental Disorders*, *43*(6), 1314–1325. https://doi.org/10.1007/s10803-012-1679-5

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, *2*, 217–250. Retrieved from https://simonsfoundation.s3.amazonaws.com/share/071207-leo-kanner-autistic-affective-contact.pdf

Keenan, M., Dillenburger, K., Röttgers, H. R., Dounavi, K., Jónsdóttir, S. L., Moderato, P., … Martin, N. (2015). Autism and ABA: The Gulf Between North America and Europe. *Review Journal of Autism and Developmental Disorders*, *2*(2), 167–183. https://doi.org/10.1007/s40489-014-0045-2

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*(4), 442–462. https://doi.org/10.1177/1362361315588200

Khanna, R., Jariwala, K., & West-Strum, D. (2013a). Use and cost of psychotropic drugs among recipients with autism in a state Medicaid fee-for-service programme. *Journal of Intellectual Disability Research*, *57*(2), 161–171. https://doi.org/https://doi.org/10.1111/j.1365-2788.2012.01563.x

Khanna, R., Jariwala, K., & West-Strum, D. (2013b). Use and cost of psychotropic drugs among recipients with autism in a state Medicaid fee-for-service programme. *Journal of Intellectual Disability Research*, *57*(2), 161–171. https://doi.org/https://doi.org/10.1111/j.1365-2788.2012.01563.x

King, B. H., Navot, N., Bernier, R., & Webb, S. J. (2014, March). Update on diagnostic classification in autism. *Current Opinion in Psychiatry*, Vol. 27, pp. 105–109. https://doi.org/10.1097/YCO.0000000000000040

Koffer Miller, K. H., Mathew, M., Nonnemacher, S. L., & Shea, L. L. (2018). Program experiences of adults with autism, their families, and providers: Findings from a focus group study. *Autism : The International Journal of Research and Practice*, *22*(3), 345–356. https://doi.org/10.1177/1362361316679000

Kornblau, B. L. (2014). *The Case for Designating People with Intellectual and Developmental Disabilities as a Medically Underserved Population*.

Lavelle, T. A., Weinstein, M. C., Newhouse, J. P., Munir, K., Kuhlthau, K. A., & Prosser, L. A. (2014). Economic burden of childhood autism spectrum disorders. *Pediatrics*, *133*(3), e520-9. https://doi.org/10.1542/peds.2013-0763

Lockwood Estrin, G., Milner, V., Spain, D., Happé, F., & Colvert, E. (2020). Barriers to Autism Spectrum Disorder Diagnosis for Young Women and Girls: a Systematic Review. *Review Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s40489-020-00225-8

Marsack, C. N., & Samuel, P. S. (2017). Mediating Effects of Social Support on Quality of Life for Parents of Adults with Autism. *Journal of Autism and Developmental Disorders*, *47*(8), 2378–2389. https://doi.org/10.1007/s10803-017-3157-6

Mason, D., Ingham, B., Urbanowicz, A., Michael, C., Birtles, H., Woodbury-Smith, M., … Parr, J. R. (2019). A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. *Journal of Autism and Developmental Disorders*, *49*(8), 3387–3400. https://doi.org/10.1007/s10803-019-04049-2

Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Research*, *11*(8), 1138–1147. https://doi.org/10.1002/aur.1965

Matson, J. L., & Kozlowski, A. M. (2011). The increasing prevalence of autism spectrum disorders. *Research in Autism Spectrum Disorders*, *5*(1), 418–425. https://doi.org/10.1016/j.rasd.2010.06.004

Mavranezouli, I., Megnin-Viggars, O., Cheema, N., Howlin, P., Baron-Cohen, S., & Pilling, S. (2014). The cost-effectiveness of supported employment for adults with autism in the United Kingdom. *Autism*, *18*(8), 975–984. https://doi.org/10.1177/1362361313505720

McConachie, H., Livingstone, N., Morris, C., Beresford, B., le Couteur, A., Gringras, P., Garland, D., Jones, G., Macdonald, G., Williams, K., & Parr, J. R. (2018). Parents Suggest Which Indicators of Progress and Outcomes Should be Measured in Young Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *48*(4), 1041–1051. https://doi.org/10.1007/s10803-017-3282-2

Medavarapu, S., Marella, L. L., Sangem, A., & Kairam, R. (2019). Where is the Evidence? A Narrative Literature Review of the Treatment Modalities for Autism Spectrum Disorders. *Cureus*. https://doi.org/10.7759/cureus.3901

Miller, J. (2021, November 5). *Low-dose PAX-101 improves autism spectrum disorder symptoms in boys*. https://www.healio.com/news/primary-care/20211104/lowdose-pax101-improves-autism-spectrum-disorder-symptoms-in-boys

Motiwala, S. S., Gupta, S., Lilly, M. B., Ungar, W. J., & Coyte, P. C. (2006). The cost-effectiveness of expanding intensive behavioural intervention to all autistic children in Ontario: in the past year, several court cases have been brought against provincial governments to increase funding for Intensive Behavioural Intervention (IBI). This economic evaluation examines the costs and consequences of expanding an IBI program. *Healthcare Policy = Politiques de Sante*, *1*(2), 135–151.

National Autism Center. (n.d.). Historical Perspective . Retrieved March 8, 2021, from May Institute website: https://www.nationalautismcenter.org/autism/historical-perspective/

National Autistic Society. (2016). *The autism employment gap: Too Much Information in the workplace*. Retrieved from https://www.basw.co.uk/resources/autism-employment-gap-too-much-information-workplace

National Collaborating Centre for Mental Health, & NICE. (2021). *AUTISM THE NICE GUIDELINE ON THE MANAGEMENT AND SUPPORT OF CHILDREN AND YOUNG PEOPLE ON THE AUTISM SPECTRUM*. Retrieved from www.nice.org.uk/guidance/cg170/chapter/1-

National Institute of Mental Health. (2018, March). Autism Spectrum Disorder. Retrieved February 2, 2021, from The National Institute of Mental Health Information Resource Center website: https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml

NHS. (2019). Where to get support if you’re autistic. Retrieved April 26, 2021, from https://www.nhs.uk/conditions/autism/support/

NICE. (n.d.). Assessment and diagnosis of autism: what to expect. Retrieved February 22, 2021, from National Institute for Health and Care Excellence website: https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/assessment-and-diagnosis-of-autism-what-to-expect

NICE. (2020). Autism in adults: how common is it? Retrieved July 16, 2021, from https://cks.nice.org.uk/topics/autism-in-adults/background-information/prevalence/

Nicholas, D. B., Zwaigenbaum, L., Zwicker, J., Clarke, M. E., Lamsal, R., Stoddart, K. P., … Lowe, K. (2018). Evaluation of employment-support services for adults with autism spectrum disorder. *Autism*, *22*(6), 693–702. https://doi.org/10.1177/1362361317702507

Oakley, B. F. M., Tillmann, J., Ahmad, J., Crawley, D., San José Cáceres, A., Holt, R., … Loth, E. (2021). How do core autism traits and associated symptoms relate to quality of life? Findings from the Longitudinal European Autism Project. *Autism*, *25*(2), 389–404. https://doi.org/10.1177/1362361320959959

Ochs, R. (2018, June). France announces €340m plan to improve autism care. Retrieved April 25, 2021, from https://www.europeanscientist.com/en/public-health/france-announces-e340m-plan-to-improve-autism-care/

Office of Autism Research Coordination. (2016). *INTERAGENCY AUTISM COORDINATING COMMITTEE strategic plan for autism spectrum disorder*. Retrieved from https://iacc.hhs.gov/publications/strategic-plan/2017/.

Ohl, A., Grice Sheff, M., Small, S., Nguyen, J., Paskor, K., & Zanjirian, A. (2017). Predictors of employment status among adults with Autism Spectrum Disorder. *Work (Reading, Mass.)*, *56*(2), 345–355. https://doi.org/10.3233/WOR-172492

Penner, M., Anagnostou, E., & Ungar, W. J. (2018). Practice patterns and determinants of wait time for autism spectrum disorder diagnosis in Canada. *Molecular Autism*, *9*(1), 16. https://doi.org/10.1186/s13229-018-0201-0

Perreault, S., Croteau, C., Mottron, L., Tarride, J., & Dorais, M. (2015). Psychiatric Healthcare Utilization and Related Costs In Newly Diagnosed Individuals With Autism Spectrum Disorder (Asd) In Quebec (Canada). *Value in Health*, *18*(7), A746–A747. https://doi.org/10.1016/j.jval.2015.09.2882

Prado, C. (2012). *Le coût économique et social de l’autisme*.

Rattaz, C., Ledesert, B., Masson, O., Ouss, L., Ropers, G., & Baghdadli, A. (2014). Special education and care services for children, adolescents, and adults with autism spectrum disorders in France: Families’ opinion and satisfaction. *Autism*, *18*(2), 185–193. https://doi.org/10.1177/1362361312460952

Rattaz, C., Michelon, C., Roeyers, H., & Baghdadli, A. (2017). Quality of Life in Parents of Young Adults with ASD: EpiTED Cohort. *Journal of Autism and Developmental Disorders*, *47*(9), 2826–2837. https://doi.org/10.1007/s10803-017-3197-y

Rogge, N., & Janssen, J. (2019). The Economic Costs of Autism Spectrum Disorder: A Literature Review. *Journal of Autism and Developmental Disorders*, *49*(7), 2873–2900. https://doi.org/10.1007/s10803-019-04014-z

Rosa, M., Puig, O., Lázaro, L., & Calvo, R. (2016). Socioeconomic status and intelligence quotient as predictors of psychiatric disorders in children and adolescents with high-functioning autism spectrum disorder and in their siblings. *Autism : The International Journal of Research and Practice*, *20*(8), 963–972. https://doi.org/10.1177/1362361315617881

Russell, G., Stapley, S., Newlove-Delgado, T., Salmon, A., White, R., Warren, F., Pearson, A., & Ford, T. (2022). Time trends in autism diagnosis over 20 years: a UK population-based cohort study. *Journal of Child Psychology and Psychiatry*, *63*(6), 674–682. https://doi.org/10.1111/jcpp.13505

Shelter Cymru. (2016). *Piecing Together A Solution: Homelessness Amongst People With Autism In Wales*. https://sheltercymru.org.uk/wp-content/uploads/2015/02/Piecing-together-a-solution-Homelessness-amongst-people-with-autism-in-Wales.pdf

Shimabukuro, T. T., Grosse, S. D., & Rice, C. (2008). Medical Expenditures for Children with an Autism Spectrum Disorder in a Privately Insured Population. *Journal of Autism and Developmental Disorders*, *38*(3), 546–552. https://doi.org/10.1007/s10803-007-0424-y

Sosnowy, C., Silverman, C., & Shattuck, P. (2018). Parents’ and young adults’ perspectives on transition outcomes for young adults with autism. *Autism : The International Journal of Research and Practice*, *22*(1), 29–39. https://doi.org/10.1177/1362361317699585

Spaulding, C. J., Lerner, M. D., & Gadow, K. D. (2016). Trajectories and correlates of special education supports for youth with autism spectrum disorder and psychiatric comparisons. *Autism*, *21*(4), 423–435. https://doi.org/10.1177/1362361316645428

Taneja, A., Sharma, S., Bhatt, N., & Kumar Bhutani, M. (2017). *Economic burden of autism* *and autism-related spectrum disorders (ASD) in EU5 countries: a systematic review PMH20 1. BresMed, Gurugram, India*. Retrieved from https://www.york.ac.uk/media/crd/Systematic_Reviews.pdf.ten Hoopen, L. W., de Nijs, P. F. A., Duvekot, J., Greaves-Lord, K., Hillegers, M. H. J., Brouwer, W. B. F., & Hakkaart-van Roijen, L. (2020). Children with an Autism Spectrum Disorder and Their Caregivers: Capturing Health-Related and Care-Related Quality of Life. *Journal of Autism and Developmental Disorders*, *50*(1), 263–277. https://doi.org/10.1007/s10803-019-04249-w

Vaincre L'Autisme. (2013). *Rapport 2013 : Situation de l'Autisme en France*. Retrieved from https://www.reseau-lucioles.org/IMG/pdf/rapport_situation_Autisme_2013_web.pdf

van Bakel, M. M. E., Delobel-Ayoub, M., Cans, C., Assouline, B., Jouk, P. S., Raynaud, J. P., & Arnaud, C. (2015). Low but Increasing Prevalence of Autism Spectrum Disorders in a French Area from Register-Based Data. *Journal of Autism and Developmental Disorders*, *45*(10), 3255–3261. https://doi.org/10.1007/s10803-015-2486-6

Van Kessel, R., Roman-Urrestarazu, A., Ruigrok, A., Holt, R., Commers, M., Hoekstra, R. A., … Baron-Cohen, S. (2019). Autism and family involvement in the right to education in the EU: Policy mapping in the Netherlands, Belgium and Germany. *Molecular Autism*, *10*(1), 43. https://doi.org/10.1186/s13229-019-0297-x

Vogeley, K., Kirchner, J. C., Gawronski, A., Van Elst, L. T., & Dziobek, I. (2013). Toward the development of a supported employment program for individuals with high-functioning autism in Germany. *European Archives of Psychiatry and Clinical Neuroscience*, *263*(SUPPL.2). https://doi.org/10.1007/s00406-013-0455-7

Vohra, R., Madhavan, S., & Sambamoorthi, U. (2017). Comorbidity prevalence, healthcare utilization, and expenditures of Medicaid enrolled adults with autism spectrum disorders. *Autism*, *21*(8), 995–1009. https://doi.org/10.1177/1362361316665222

Wang, L., Mandell, D. S., Lawer, L., Cidav, Z., & Leslie, D. L. (2013). Healthcare Service Use and Costs for Autism Spectrum Disorder: A Comparison Between Medicaid and Private Insurance. *Journal of Autism and Developmental Disorders*, *43*(5), 1057–1064. https://doi.org/10.1007/s10803-012-1649-y

Weiss, J. A., Isaacs, B., Diepstra, H., Wilton, A. S., Brown, H. K., McGarry, C., & Lunsky, Y. (2018). Health Concerns and Health Service Utilization in a Population Cohort of Young Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *48*(1), 36–44. https://doi.org/10.1007/s10803-017-3292-0

WHO. (2013, September). *Autism spectrum disorders & other developmental disorders: From raising awareness to building capacity*.

Yang, Y. J. D., Allen, T., Abdullahi, S. M., Pelphrey, K. A., Volkmar, F. R., & Chapman, S. B. (2018). Neural mechanisms of behavioral change in young adults with high-functioning autism receiving virtual reality social cognition training: A pilot study. *Autism Research*, *11*(5), 713–725. https://doi.org/10.1002/aur.1941

Zablotsky, B., Anderson, C., & Law, P. (2013). The Association Between Child Autism Symptomatology, Maternal Quality of Life, and Risk for Depression. *Journal of Autism and Developmental Disorders*, *43*(8), 1946–1955. https://doi.org/10.1007/s10803-012-1745-z

Zablotsky, B., Bradshaw, C. P., Anderson, C. M., & Law, P. (2014). Risk factors for bullying among children with autism spectrum disorders. *Autism : The International Journal of Research and Practice*, *18*(4), 419–427. https://doi.org/10.1177/1362361313477920

Zeldovich, L. (2018, May 9). The evolution of "autism" as a diagnosis, explained. Retrieved March 8, 2021, from Spectrum News website: https://www.spectrumnews.org/news/evolution-autism-diagnosis-explained/

Zero Project. (2016). In Italy, students with disabilities are not segregated . Retrieved April 26, 2021, from https://zeroproject.org/policy/in-italy-students-with-disabilities-are-not-segregated/

Appendices

Appendix Table 1. Types of education experienced across countries and across gender.

	Country							Total (n=1141)	Gender		
	Canada (n=23)	France (n=76)	Germany (n=59)	Italy (n=23)	Spain (n=50)	UK (n=835)	USA (n=75)		Male (n=438)	Female (n=613)	Other Identity (n=90)
Primary School	5 (21.7%)	23 (30.3%)	17 (28.8%)	7 (30.4%)	16 (32%)	263 (31.5%)	21 (28%)	352 (30.9%)	140 (12.3%)	183 (16%)	27 (2.4%)
Secondary School	7 (30.4%)	22 (28.9%)	23 (39%)	7 (30.4%)	13 (26%)	233 (27.9%)	23 (30.7%)	328 (28.7%)	121 (10.6%)	177 (15.5%)	28 (2.5%)
University	4 (17.4%)	10 (13.2%)	9 (15.3%)	5 (21.7%)	1 (2%)	143 (17.1%)	14 (18.7%)	186 (16.3%)	62 (5.4%)	109 (9.6%)	15 (1.3%)
Postgraduate	3 (13%)	10 (13.2%)	0%	2 (8.7%)	1 (2%)	83 (9.9%)	5 (6.7%)	104 (9.1%)	37 (3.2%)	59 (5.2%)	8 (0.7%)
Vocational Training	2 (8.7%)	6 (7.9%)	6 (10.2%)	0%	0%	48 (5.7%)	4 (5.3%)	66 (5.8%)	22 (1.9%)	38 (3.3%)	9 (0.8%)
Special Educational School	1 (4.3%)	2 (2.6%)	3 (5.1%)	1 (4.3%)	15 (30%)	43 (5.1%)	3(4%)	68 (6%)	40 (3.5%)	25 (2.2%)	2 (0.2%)
Home-schooling	1 (4.3%)	3 (3.9%)	1 (1.7%)	1 (4.3%)	4 (8%)	22 (2.6%)	5 (6.7%)	37 (3.2%)	16 (1.4%)	22 (1.9%)	1 (0.1%)

Appendix Table 2. Types of support available to respondents from their educational institution.

Type of Support	Type of Education						Range
	Primary n=264	Secondary n=218	University n=119	Postgraduate n=79	Vocational School n=45	Special Educational School n=219	
One-to-one support	58 (22%)	44 (20.2%)	31 (26.1%)	28 (35.4%)	16 (35.6%)	35 (16%)	16%-35.6%
Counselling	17 (6.4%)	23 (10.6%)	18 (15.1%)	12 (15.2%)	1 (2.2%)	14 (6.4%)	2.2%-15.2%
Extra time	29 (11%)	47 (21.6%)	38 (31.9%)	18 (22.8%)	12 (26.7%)	15 (6.8%)	6.8%-31.9%
Small unit-based teaching	40 (15.2%)	37 (17%)	9 (7.6%)	4 (5.1%)	8 (17.8%)	37 (16.9%)	5.1%-17.8%
Sensory room	13 (4.9%)	7 (3.2%)	1 (0.8%)	2 (2.5%)	3 (6.7%)	28 (12.8%)	0.8%-12.8%
Down time	33 (12.5%)	30 (13.8%)	8 (6.7%)	6 (7.6%)	5 (11.1%)	25 (11.4%)	6.7%-13.8%
Buddy support	18 (6.8%)	11 (5%)	5 (4.2%)	5 (6.3%)	0 (0%)	8 (3.7%)	0%-6.8%
Visual timetables	37 (14%)	15 (6.9%)	9 (7.6%)	2 (2.5%)	0 (0%)	33 (15.1%)	0%-15.1%
Picture exchange communication systems	19 (7.2%)	4 (1.8%)	0 (0%)	2 (2.5%)	0 (0%)	25 (11%)	0%-7.2%

Appendix Table 3. Discrimination experienced at the educational environment while unaware of autism diagnosis.

	Country							Total (n=222)	Gender		
Primary	**Canada (*n=2)**	**France (n=16)**	**Germany (n=14)**	**Italy (n=3)**	**Spain (n=7)**	**UK (n=168)**	**USA (n=12)**		**Male (n=84)**	**Female (n=118)**	**Other identity (n=19)**
Of yes, were unaware†	2 (100%)	14 (87.5%)	12 (87.5%)	0 (0%)	2 (28.6%)	111 (66.1%)	9 (75%)	150 (67.6%)	49 (58%)	84 (71%)	16 (84%)
Secondary	**Canada (n=3)**	**France (n=12)**	**Germany (n=20)**	**Italy (n=5)**	**Spain (n=3)**	**UK (n=164)**	**USA (n=16)**	**Total (n=223)**	**Male (n=77)**	**Female (n=123)**	**Other identity (n=24)**
Of yes, were unaware	2 (66.7%)	12 (100%)	15 (75%)	2 (40%)	1 (33.3%)	122 (74.4%)	11 (68.8%)	165 (74%)	48 (62%)	98 (80%)	17 (71%)
University	**Canada (n=1)**	**France (n=2)**	**Germany (n=3)**	**Italy (n=1)**	**Spain (n=1)**	**UK (n=62)**	**USA (n=7)**	**Total (n=77)**	**Male (n=27)**	**Female (n=47)**	**Other identity (n=3)**
Of yes, were unaware	1 (100%)	2 (100%)	3 (100%)	1 (100%)	1 (100%)	44 (71%)	3 (42.9%)	55 (71.4%)	21 (77.8%)	32 (68.1%)	2 (66.7%)
Postgraduate	**Canada (n=0)**	**France (n=3)**	**Germany (n=0)**	**Italy (n=0)**	**Spain (n=0)**	**UK (n=33)**	**USA (n=2)**	**Total (n=38)**	**Male (n=12)**	**Female (n=23)**	**Other identity (n=3)**
Of yes, were unaware	n/r‡	2 (66.7%)	n/r	n/r	n/r	22 (66.7%)	2 (100%)	26 (68.4%)	10 (83.3%)	14 (60.9%)	2 (66.7%)
Vocational School	**Canada (n=1)**	**France (n=2)**	**Germany (n=6)**	**Italy (n=0)**	**Spain (n=0)**	**UK (n=29)**	**USA (n=2)**	**Total (n=40)**	**Male (n=13)**	**Female (n=22)**	**Other identity (n=5)**
Of yes, were unaware	1 (100%)	2 (100%)	6 (100%)	n/r	n/r	22 (75.9%)	2 (100%)	33 (83%)	12 (92.3%)	18 (81.8%)	3 (60%)
Special Education	**Canada (n=0)**	**France (n=1)**	**Germany (n=2)**	**Italy (n=0)**	**Spain (n=4)**	**UK (n=15)**	**USA (n=1)**	**Total (n=23)**	**Male (n=14)**	**Female (n=8)**	**Other identity (n=1)**
Of yes, were unaware	n/r	1 (100%)	0 (0%)	n/r	1 (25%)	2 (13.3%)	0 (0%)	4 (17%)	3 (21.4%)	1 (12.5%)	0 (0%)

Key:

*: Total "n" reflects the number of respondents who experienced discrimination, those who answered "Yes" and "Yes, I was discriminated against but it was not known at the time that I was autistic."

†: "Of yes, were unaware" reflects those respondents who answered "Yes, I was discriminated against but it was not known at the time that I was autistic."

‡: n/r indicates no responses

Appendix Table 4. Respondent experience of discrimination in the workplace.

	Experience of discrimination across countries								Response by gender (% out of total respondents per gender)		
	Canada (n = 8)	**France (n=23)**	**Germany (n=24)**	**Italy (n=14)**	**Spain (n = 20)**	**UK (n = 212)**	**USA (n = 24)**	**Total (n = 325)**	**Male (n = 124)**	**Female (n = 174)**	**Other identity (n = 27)**
No, not at all	3 (37.5%)	3 (13%)	4 (16.7%)	9 (64.3)	12 (60%)	43 (20.3%)	8 (33.3%)	82 (25.3%)	36 (29%)	41 (23.6%)	5 (18.5%)
Yes, somewhat	4 (50%)	3 (13%)	6 (25%)	1 (7.1%)	0%	51 (24.1%)	8 (33.3%)	73 (22.5%)	29 (23.4%)	40 (23%)	4 (14.8%)
Yes, a great deal	1 (12.5%)	6 (26.1%)	6 (25%)	0 (0%)	1 (5%)	70 (33%)	5 (20.8%)	89 (27.4%)	32 (25.8%)	49 (28.2%)	8 (29.9%)
Do not know	0%	11 (47.8%)	8 (33.3%)	4 (28.6%)	7 (35%)	48 (22.6%)	3 (12.5%)	81 (24.9%)	27 (21.8%)	44 (25.3%)	10 (37%)

Appendix Table 5. Living arrangements and accommodation for both adults and children across countries and gender.

Adults	**Accommodation types across countries**								**Response by gender (% out of total respondents per answer option)**		
	Canada n = 8	**France n = 28**	**Germany n = 28**	**Italy n = 16**	**Spain n = 29**	**UK n = 240**	**USA n = 27**	**Total n = 376**	**Male n = 147**	**Female n = 199**	**Other identity n = 30**
With parents or other family members acting as supporters	2 (25%)	6 (21.4%)	6 (21.4%)	7 (43.8%)	20 (69%)	55 (22.9%)	7 (25.9%)	103 (27.4%)	50 (34%)	49 (24.6%)	4 (13.3%)
Independently with partner/family members not acting as supporters	3 (37.5%)	8 (28.6%)	9 (32.1%)	5 (31.3%)	2 (6.9%)	85 (35.4%)	9 (33.3%)	121 (32.2%)	40 (27.2%)	71 (35.7%)	10 (33.3%)
On own (or with partner) with additional social support/homecare	0 (0%)	0 (0%)	2 (7.1%)	0 (0%)	3 (10.3%)	8 (3.3%)	0 (0%)	13 (3.5%)	4 (2.7%)	7 (3.5)	2 (6.7%)
Independently alone	2 (25%)	11 (39.3%)	4 (14.3%)	3 (18.8%)	2 (6.9%)	44 (18.3%)	7 (25.9%)	73 (19.4%)	28 (19%)	38 (19.1)	7 (23.3%)
In supported accommodation	0 (0%)	0 (0%)	1 (3.6%)	0 (0%)	0 (0%)	3 (1.3%)	1 (3.7%)	5 (1.3%)	4 (2.7%)	1 (0.5%)	0 (0%)
In a group home / care home	0 (0%)	1 (3.6%)	0 (0%)	1 (6.3%)	2 (6.9%)	1 (0.4%)	0 (0%)	5 (1.3%)	4 (2.7%)	1 (0.5%)	0 (0%)
Other	1 (12.5%)	2 (7.1%)	1 (21.4%)	0 (0%)	0 (0%)	44 (18.3%)	3 (11.1%)	56 (14.9%)	17 (11.6%)	32 (16.1%)	7 (23.3%)
Children (under 18)	**Canada n = 0**	**France n = 3**	**Germany n = 7**	**Italy n = 2**	**Spain n = 10**	**UK n = 46**	**USA n = 3**	**Total n = 71**	**Male n = 47**	**Female n = 22**	**Other identity n = 2**
With parents or other family members acting as supporters	0 (0%)	3 (100%)	7 (100%)	2 (100%)	10 (100%)	45 (97.8%)	3 (100%)	70 (98.6%)	47 (100%)	22 (100%)	1 (50%)
Independently with partner/family members not acting as supporters	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2.2%)	0 (0%)	1 (1.41%)	0 (0%)	0 (0%)	1 (50%)
On own (or with partner) with additional social support/homecare	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Independently alone	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
In supported accommodation	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
In a group home / care home	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Other	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

Appendix Table 6. Support received to find accommodation, for both adults and children across countries and gender, adjusted for respondents where support is applicable to their situation.

	Receipt of support across countries								Response by gender (% out of total respondents per gender)		
Adults	**Canada n = 6**	**France n = 21**	**Germany n = 22**	**Italy n = 12**	**Spain n = 21**	**UK n = 177**	**USA n = 23**	**Total n = 282**	**Male n = 110**	**Female n = 152**	**Other identity n = 20**
• Yes	0 (0%)	3 (14.3%)	4 (18.2%)	3 (25%)	9 (42.9%)	11 (6.2%)	7 (30.4%)	37 (19.6%)	23 (21%)	13 (9%)	1 (5%)
• No	6 (100%)	18 (85.7%)	18 (81.8%)	9 (75%)	12 (57.1%)	166 (93.8%)	16 (69.6%)	245 (80.4%)	87 (79%)	139 (91%)	19 (95%)
Children	**Canada n = 0**	**France n = 1**	**Germany n = 2**	**Italy n = 1**	**Spain n = 4**	**UK n = 10**	**USA n = 1**	**Total n = 19**	**Male n = 13**	**Female n = 6**	**Other identity n = 0**
• Yes	0 (0%)	0 (0%)	1 (50%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (5.3%)	1 (8%)	0 (0%)	0 (0%)
• No	0 (0%)	1 (100%)	1 (50%)	1 (100%)	4 (100%)	10 (100%)	0 (0%)	18 (94.7%)	12 (92%)	6 (100%)	0 (0%)

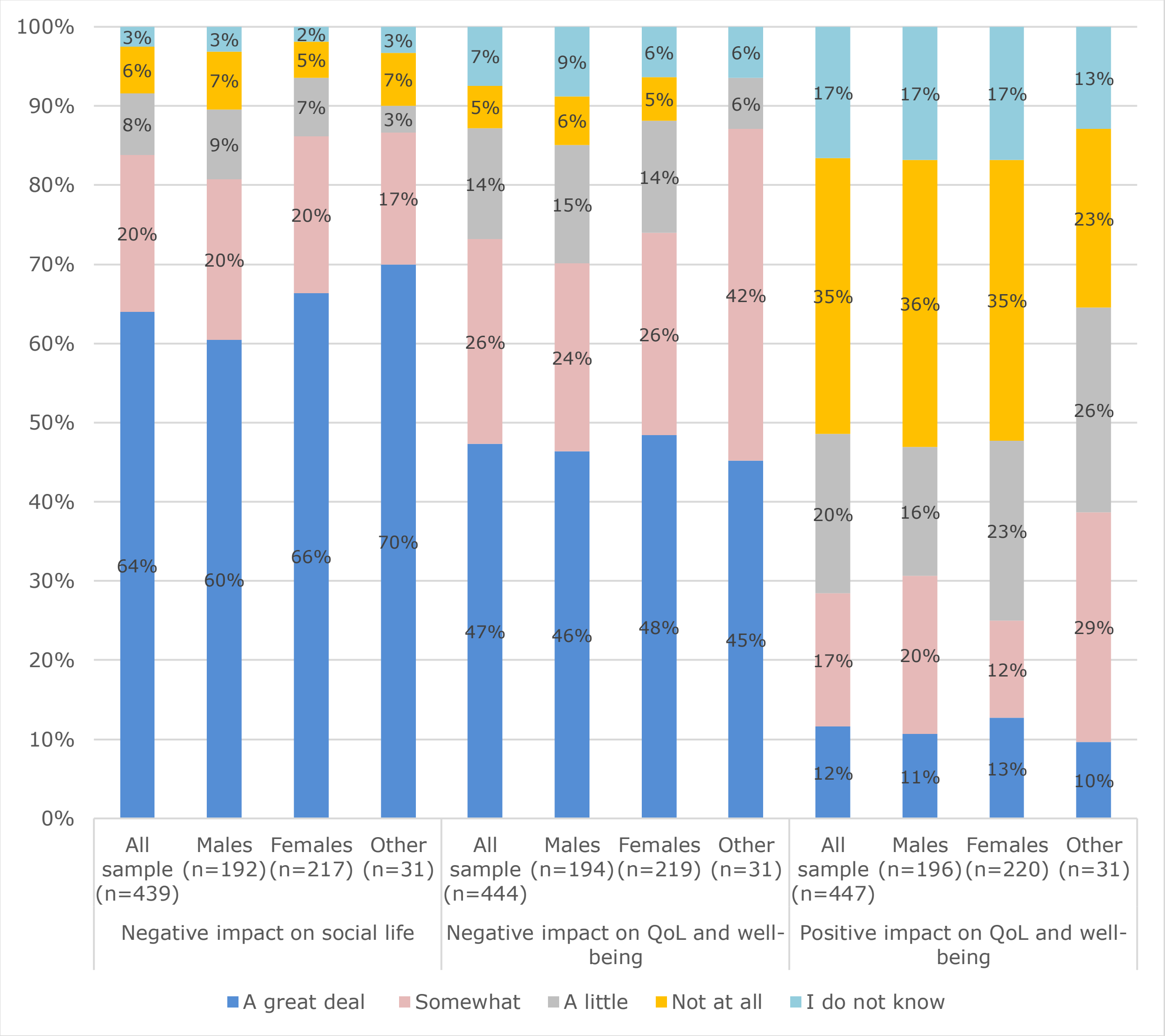
Appendix Table 7. Current support for living arrangements, for both adults and children across countries and gender, adjusted for respondents where support is applicable to their situation.

	Receipt of support across countries								Response by gender (% out of total respondents per gender)		
Adults	**Canada n = 8**	**France n =23**	**Germany n = 23**	**Italy n = 14**	**Spain n = 18**	**UK n = 196**	**USA n = 25**	**Total n = 307**	**Male n = 114**	**Female n = 166**	**Other identity n = 27**
Yes	3 (37.5%)	1 (4.3%)	6 (26.1%)	4 (28.6%)	9 (50%)	31(15.8%)	11 (44%)	65 (29.5%)	27 (24%)	33 (20%)	5 (19%)
No	5 (62.5%)	22 (95.7%)	17 (73.9%)	10 (71.4%)	9 (50%)	165 (84.2%)	14 (56%)	242 (70.5%)	87 (76%)	133 (80%)	22 (81%)
Children	**Canada n = 0**	**France n = 1**	**Germany n = 3**	**Italy n = 2**	**Spain n = 4**	**UK n = 11**	**USA n = 1**	**Total n = 22**	**Male n = 16**	**Female n = 5**	**Other identity n = 1**
Yes	0 (0%)	0 (0%)	1 (33.3%)	0 (0%)	0 (0%)	2 (18.2%)	1 (100%)	4 (5.3%)	1 (6%)	2 (40%)	1 (100%)
No	0 (0%)	1 (100%)	2 (66.7%)	2 (100%)	4 (100%)	9 (81.8%)	0 (0%)	18 (94.7%)	15 (94%)	3 (60%)	0 (0%)

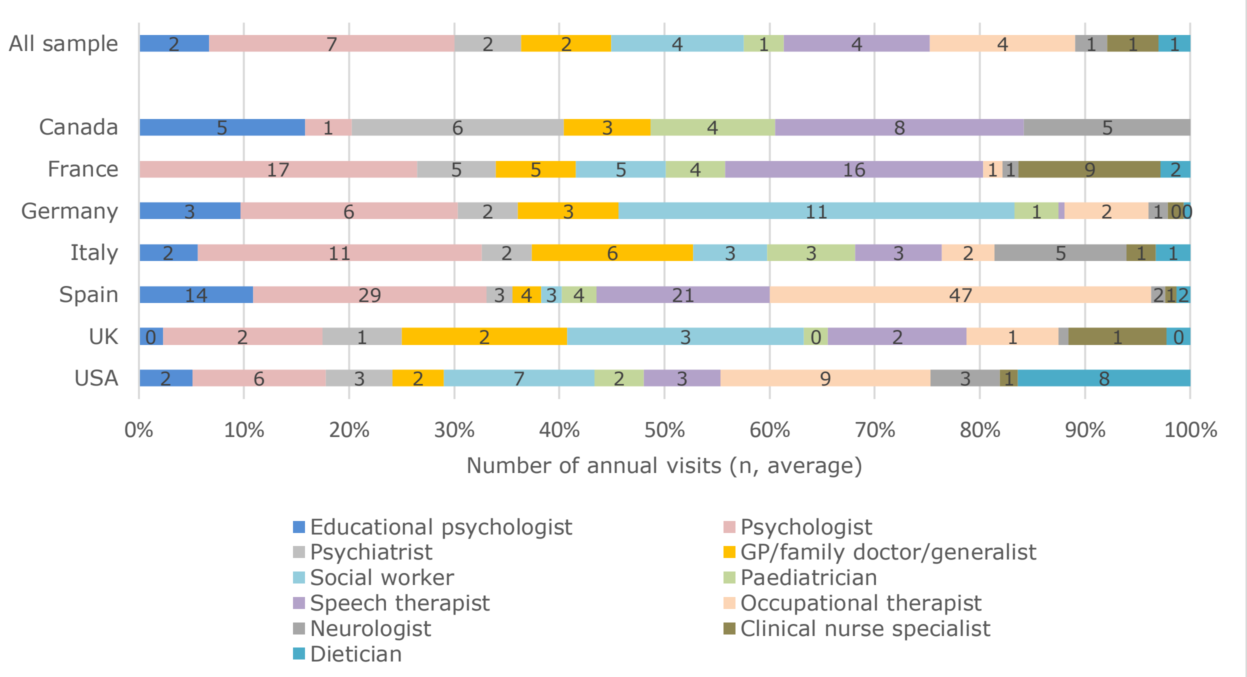
Appendix Table 8. Desire to live more independently for adults and children across countries and gender.

	Desire to live more independently								Response by gender (% out of total respondents per gender)		
Adults	**Canada n = 8**	**France n = 25**	**Germany n = 27**	**Italy n = 16**	**Spain n = 27**	**UK n = 228**	**USA n = 27**	**Total n = 358**	**Male n = 142**	**Female n = 187**	**Other identity n = 29**
Yes	1 (12.5%)	8 (32%)	10 (37%)	5 (31.3%)	5 (18.5%)	77 (33.8%)	6 (22.2%)	112 (31.3%)	43 (30.3%)	55 (29.4%)	14 (48.3%)
Not right now, but potentially in the future	3 (37.5%)	9 (36%)	12 (44.4%)	2 (12.5%)	14 (51.9%)	43 (18.9%)	4 (14.8%)	87 (24.3%)	32 (22.5%)	50 (27.7%)	5 (17.2%)
No	4 (50%)	8 (32%)	5 (18.5%)	9 (56.3%)	8 (29.6%)	108 (47.4%)	17 (63%)	159 (44.4%)	67 (47.2%)	82 (43.9%)	10 (34.5%)
Children	**Canada n = 0**	**France n = 3**	**Germany n = 7**	**Italy n = 2**	**Spain n = 8**	**UK n = 45**	**USA n = 3**	**Total n = 68**	**Male n = 46**	**Female n = 20**	**Other identity n = 2**
Yes	0 (0%)	1 (33.3%)	0 (0%)	2 (100%)	2 (25%)	10 (22.2%)	0 (0%)	15 (22.1%)	12 (26%)	3 (15%)	0 (0%)
Not right now, but potentially in the future	0 (0%)	2 (66.7%)	5 (71.4%)	0 (0%)	6 (75%)	32 (71.1%)	3 (100%)	48 (70.6%)	33 (72%)	13 (65%)	2 (100%)
No	0 (0%)	0 (0%)	2 (28.6%)	0 (0%)	0 (0%)	3 (6.7%)	0 (0%)	5 (7.4%)	1 (2%)	4 (20%)	0 (0%)

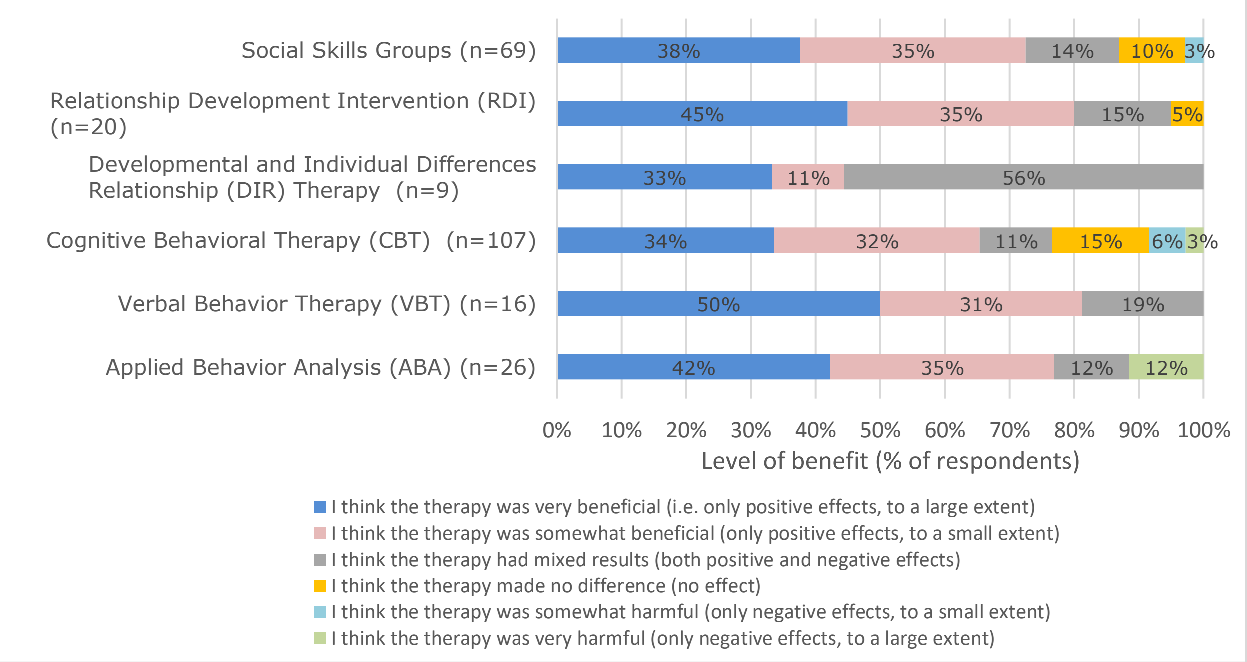
Appendix Figure 1. Self-rated level of impact of autism on autistic individuals' QoL, well-being and social life, across all sample and across male, females and "other" gender categories.



Appendix Figure 2. Average number of annual visits to healthcare professionals, across countries.



Appendix Figure 3. Self-rated level of benefit from interventional therapies received by autistic individuals across all sample.



Appendix Figure 4. Supporters' self-rating on how they feel about various aspects relevant to caring for an autistic person.