



BMJ Open COVID-19 health and social care access for autistic people: European policy review

Bethany Oakley,¹ Julian Tillmann ,^{2,3} Amber Ruigrok,⁴ Aurélie Baranger,⁵ Christian Takow,⁵ Tony Charman ,^{2,6} Emily Jones,⁷ James Cusack,⁸ Mary Doherty,⁹ Pierre Violland,⁵ Agnieszka Wroczyńska,¹⁰ Emily Simonoff,¹¹ Jan K Buitelaar,^{12,13} Louise Gallagher,¹⁴ Declan G M Murphy,^{1,15} AIMS-2-TRIALS ECRAN & the AIMS-2-TRIALS Consortium

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For numbered affiliations see end of article.

Correspondence to

Dr Bethany Oakley;
bethany.oakley@kcl.ac.uk

ABSTRACT

Background The global COVID-19 pandemic has had an unprecedented impact on European health and social care systems, with demands on testing, hospital and intensive care capacity exceeding available resources in many regions. This has led to concerns that some vulnerable groups, including autistic people, may be excluded from services.

Methods We reviewed policies from 15 European member states, published in March–July 2020, pertaining to (1) access to COVID-19 tests; (2) provisions for treatment, hospitalisation and intensive care units (ICUs); and (3) changes to standard health and social care. In parallel, we analysed survey data on the lived experiences of 1301 autistic people and caregivers.

Results Autistic people experienced significant barriers when accessing COVID-19 services. First, despite being at elevated risk of severe illness due to co-occurring health conditions, there was a lack of accessibility of COVID-19 testing. Second, many COVID-19 outpatient and inpatient treatment services were reported to be inaccessible, predominantly resulting from individual differences in communication needs. Third, ICU triage protocols in many European countries (directly or indirectly) resulted in discriminatory exclusion from lifesaving treatments. Finally, interruptions to standard health and social care left over 70% of autistic people without everyday support.

Conclusions The COVID-19 pandemic has further exacerbated existing healthcare inequalities for autistic people, probably contributing to disproportionate increases in morbidity and mortality, mental health and behavioural difficulties, and reduced quality of life. An urgent need exists for policies and guidelines on accessibility of COVID-19 services to be updated to prevent the widespread exclusion of autistic people from services, which represents a violation of international human rights law.

INTRODUCTION

Over 26 million SARS-CoV2 infections (hereafter COVID-19) and 550 000 COVID-19-related deaths had been confirmed in Europe by the close of 2020, making it one of the worst hit regions worldwide.¹

Strengths and limitations of this study

- Comprehensive review of regional and national policies and guidelines on access to COVID-19 health and social care services from 15 European countries.
- Large-scale survey of the lived experiences of 1301 individuals from the autism community, capturing real-world COVID-19 health and social care provision.
- Synthesis of policy and survey findings in the context of a multi-disciplinary, participatory collaboration, including autistic people, non-profit autism stakeholder organisations, clinical experts and researchers from across Europe.
- Nuanced analysis and comparison of regional and national service provision is challenging due to variation in health and social care systems and a lack of available policy or survey data in some European countries.
- Self-selection of survey respondents and variation in the impact of COVID-19 across European countries might have introduced response or publication biases that influenced the information available for this study.

During global viral pandemics and public health emergencies, like COVID-19, there is a significant risk that overwhelming and sustained demand for healthcare resources could exceed the capacity of healthcare systems.^{2 3} Consequently, mitigation measures to reduce pressure on health and social care systems have been implemented in many regions, including strict national lockdown policies (ie, restrictions on movement) to slow virus transmission.⁴ Nevertheless, within just 1 month of COVID-19 being declared a global pandemic, the European Centre for Disease Prevention and Control reported that many EU countries were experiencing unprecedented demands on testing capacity, personal protective equipment

(PPE), and hospital and intensive care capacity, far exceeding available resources.⁵ In such situations, disparities in healthcare access are magnified, leading to concerns that some groups of individuals, including autistic people, might be particularly vulnerable to being excluded from services, support and treatment in pandemic situations.⁶

Reports from the United States during the first global peak of COVID-19 infection indicated inequalities in access to COVID-19 services, with one study highlighting that 27 states had adopted ‘healthcare rationing’ policies that could harm autistic people and those with disabilities (including intellectual disability).⁷ Furthermore, COVID-19 may disproportionately impact autistic people (who represent at least 1% of European citizens and at least 32% of whom have a co-occurring intellectual disability)^{8,9} due to elevated physical health comorbidities and existing healthcare inequalities. For example, physical health conditions are experienced at substantially higher rates by autistic people compared with the general population, including conditions associated with high risk of severe illness from COVID-19 (eg, cardiovascular or immune conditions, diabetes, obesity).^{10–12} In addition, autistic people experience numerous existing barriers to accessing general healthcare,¹³ which may also increase their risk of being excluded from COVID-19 services. These barriers include communication or interpretation difficulties, which can lead to misunderstandings by healthcare providers and reduced involvement of patients in healthcare decision making (and might be exacerbated by mask wearing, which reduces the availability of non-verbal facial cues during interaction); difficulties adjusting to change and novel procedures; sensory sensitivities (eg, around physical examinations, mask wearing); difficulties identifying or describing pains and symptoms; and inconsistent specialist clinician training, awareness and knowledge about autism and intellectual disability.^{13–15} Health providers might also misattribute COVID-19 symptoms to existing medical, mental health or behavioural problems, or autism itself (‘diagnostic overshadowing’), increasing the risk of severe disease due to missed or late diagnosis.¹⁶

Difficulties and delays in accessing COVID-19 services may partly explain why the UK death rate of people with intellectual disability (some of whom are also autistic) increased by 134% in the period from mid-April to May 2019 compared with 2020, notably higher than in the total population, where deaths increased by 80%.^{17,18} Additionally, at least 40–60% of confirmed deaths from COVID-19 across European countries with community transmission are believed to have occurred in long-term care facilities,¹⁹ a proportion of which offer residential care for autistic people. Of further concern, although guidelines around COVID-19 management and intellectual disability were released by the World Health Organization in March 2020²⁰ and more detailed information has since been published by charities and clinical research teams,^{21–23} the extent to which these recommendations

were distributed and implemented within national policies across Europe to safeguard autistic people is unclear.

We collated and reviewed regional or national policies and guidelines from 15 European member states, covering three priority areas: (1) access to COVID-19 testing and screening; (2) provisions for treatment, hospitalisation and access to intensive care units (ICUs); and (3) access to standard health and social care. We considered whether current guidelines (directly or indirectly) discriminate against (or are protective of) autistic people. Furthermore, to capture lived experiences of COVID-19 health and social care provision at the level of the individual, Autism-Europe provided secondary data from a large-scale survey of autistic people and caregivers.

METHODS

Study design

AIMS-2-TRIALS is an international public–private partnership that brings together autistic people and their families, researchers and clinicians, charities, industry and pharmaceutical companies to improve understanding of autism and enhance treatment options for autistic people (<https://www.aims-2-trials.eu/>). To assess COVID-19 health and social care provision for autistic people, according to the priority areas described above, a two-step methodological approach was implemented. First, COVID-19 health and social care policies from 15 European countries were collated and reviewed by researchers, clinicians and non-profit groups from the AIMS-2-TRIALS Clinical Trials and Early Career Researchers in Autism Networks, and a panel of five representatives from the autism community.

Second, Autism-Europe provided de-identified secondary data from their large-scale survey of the impact of COVID-19 on 1301 autistic people and caregivers. An overview of the European countries represented in this review is presented in [figure 1](#) and Autism-Europe respondent characteristics in online supplemental table 1.

Materials and procedures

Review of European COVID-19 policy and guidelines

COVID-19-related policies and guidelines from 15 European countries ([figure 1](#)) were assessed using a common review template (please see online supplemental material 1), indexing three priority areas: access to testing and screening; access to treatment, hospital and intensive care resources; and changes to existing health and social care. To be included, policies and guidelines had to be publicly available (ie, online/open access) and published between March and July 2020. A full list of included documents is provided in online supplemental table 2, with source of access specified.

Policies and guidelines were collated and translated into English by a panel of 30 AIMS-2-TRIALS early career autism researchers and five representatives from the autism community. In addition, documents were reviewed

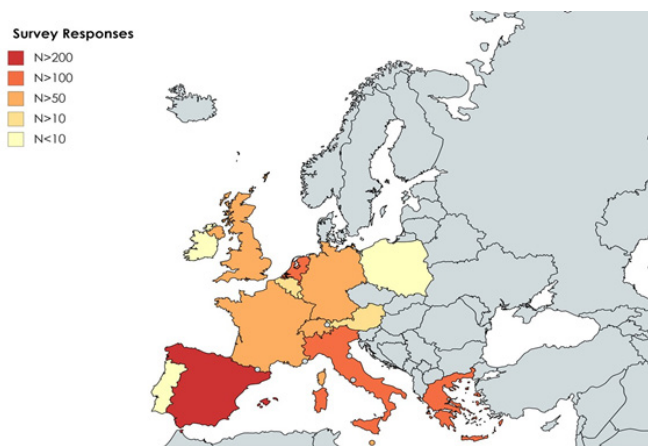


Figure 1 Schematic highlighting the 15 European countries included in this study, colour coded by number of Autism-Europe survey responses from each region: Spain, n=304; Italy, n=192; Greece, n=165; the Netherlands, n=143; Switzerland, n=144; France, n=86; United Kingdom, n=66; Germany, n=60; Malta, n=53; Belgium, n=34; Luxembourg, n=33; Austria, n=12; Ireland, n=5; Poland, n=3; Portugal, n=1.

by clinicians with extensive experience in autism diagnosis and intervention, who provided expert commentary.

Lived experiences from the autism community

As noted in the Introduction, where specific guidance has been published, the extent to which recommendations for supporting autistic people and those with intellectual disability have been implemented in everyday practice is unclear. Thus, alongside our policy review, Autism-Europe (an international, non-profit organisation: <https://www.autismeurope.org/>) also provided de-identified secondary data from their independent, large-scale survey of experiences of the COVID-19 pandemic from the autism community.

For the purposes of this review, we included Autism-Europe survey responses from the 15 countries for which we also had access to published policy or guidelines. We excluded respondents who were not autistic, or relatives/caregivers (as the identity of ‘other’ respondents were not clearly defined), and those who opened but did not answer survey questions. This resulted in a final convenience sample of 1301: 346 autistic people and 955 caregivers. Please see online supplemental table 1 for survey demographics.

Survey items requested from Autism-Europe for the purpose of this review are documented in online supplemental table 3. The survey was disseminated publicly online between 7 April and 31 May 2020, in 10 languages, with participants recruited via Autism-Europe, UK autism charities and social media. Administration of the survey was conducted under the ‘Rights, Equality and Citizenship programme 2014–2020’, funded by the European Commission. Respondents were notified of the Autism-Europe GDPR policy that responses would be used for the development of policy recommendations, and gave

written permission for the publication of their anonymised quotations, which were included for illustrative purposes.

Public and patient involvement

Representatives from the autism community, and charities Autism-Europe and Autistica, were involved as active research partners in all aspects of the research through identifying priority areas for policy review, collating and reviewing policy guidelines in selected countries, interpreting findings, making recommendations for policy guidance, and editing or co-authoring the manuscript. Autism-Europe independently designed the survey content and collated all responses.

RESULTS

Review of European COVID-19 policy or guidelines (March–July 2020)

Accessibility of COVID-19 testing and screening

First, we considered guidance on access to COVID-19 tests, particularly in the context of testing shortages. As explicitly acknowledged in documentation released by several European regions reviewed in this study—including the UK, the Netherlands and Belgium^{24–26}—those with relevant physical comorbidities and/or living in residential care meet criteria for priority COVID-19 testing. This guidance is relevant for autistic people, given a high proportion experience physical health comorbidities that are associated with increased risk of developing severe disease on contracting COVID-19, including cardiovascular or respiratory illness, autoimmune conditions, diabetes, obesity and hypertension.

Second, approximately 5–25% of autistic people live in residential care (ie, higher intensity nursing or large group homes) and up to a further 27% in supported accommodation (ie, lower intensity congregate care settings in the community), with upper bound estimates referring to those with co-occurring intellectual disability.²⁷ This is notable because the transmission rate of COVID-19 in residential care settings is high due to factors such as care staff interacting with multiple residents throughout the day; global shortages of PPE and testing for care staff; difficulties for some individuals with strict adherence to personal hygiene practices; and impracticalities of maintaining physical distancing (eg, if residents require personal care).^{28 29}

Despite existing evidence of increased risk of poor outcomes from COVID-19 for autistic people, our review indicated that they have not been routinely specified for priority access to testing across Europe. For instance, early in the COVID-19 pandemic, many regions with testing shortages initially prioritised essential workers and those hospitalised with suspected COVID-19 symptoms.³⁰ In the UK and Ireland, care home residents (including those who were asymptomatic) were not officially added to the list for priority access to COVID-19 testing until 29 and 17 April 2020, respectively, at least

2 months after the first confirmed COVID-19 cases in these regions.^{26 31} Similarly, other countries that did not initially identify individuals in residential care settings as priority for testing, including the Netherlands and Belgium,^{24 25} now prioritise these groups; the Netherlands is the only country to directly prioritise individuals with serious behavioural problems in residential care for testing.

However, we did not identify any additional published guidance, or strategies specifically for enhancing accessibility of testing for autistic people across any other country reviewed in this study. For instance, even in the countries identified above where individuals with certain physical comorbidities and those living in 'high risk' settings were prioritised for access to testing in case of shortages, there was no guidance published for those living in supported accommodation and the community. A lack of guidance was also identified for enhancing the tolerability (and thus accessibility) of test procedures for autistic people. For example, sensory sensitivities and difficulties around uncertainty and changes in routine are highly associated with autism,^{32 33} and COVID-19 diagnostic tests frequently involve nasal and throat swabs or aspiration,³⁴ use of necessary PPE (a potential sensory and communication barrier), long waiting times and travel to an unfamiliar location—sometimes without the option to be accompanied by a caregiver.

Access to treatment or hospitalisation

Next, we reviewed current recommendations for the treatment and admission to hospital of autistic people who have COVID-19. Findings first highlighted that guidance from several European countries, including Belgium, Italy and the Netherlands, currently recommends that autistic people and those with behavioural problems are treated for COVID-19 within existing designated specialist neurodevelopmental or neuropsychiatric pathways, rather than general hospital settings.^{35 36}

This approach may have some benefit in access to a greater range of specialist staff and resources to adequately support individuals with additional needs, as well as providing more flexibility around some regulations (eg, allowing visitation by a caregiver or support person, with appropriate hygiene measures in place).

Nevertheless, in an open letter to EU leaders, the European Disability Forum specifically recommended that 'persons with disabilities should not be segregated into separate facilities, where healthcare for COVID-19 is often of a lower standard'.³⁷ Examples of concerns about COVID-19 care provision in neurodevelopmental or psychiatric pathways include shortages of staff with medical or surgical and psychiatric expertise and experience. In addition, there are challenges for controlling infection spread in neurodevelopmental or psychiatric inpatient settings due to factors like close contact between patients and care providers and shortages of PPE, for which general hospitals may be prioritised.³⁸

Access to intensive care

Our review indicated that—where officially documented—interpretation of ICU triage protocols and policies could pose a barrier to equitable care and access to lifesaving treatments (please see [table 1](#)).

For example, several European countries with published triage protocols recommend the consideration of 'functional status' and/or the use of 'frailty assessments', including the UK, Ireland, France, the Netherlands, Italy, Belgium, Austria and Germany.^{39–47} These assessments were originally designed with reference to elderly populations to determine individuals with very poor prognosis for recovery from their current illness.⁴⁸ Despite this, concerns have been raised over ambiguity in some current guidance on the application and interpretation of frailty assessments, whereby the support needs of some autistic people may be conflated with 'frailty'.^{37 49 50} As an example, frailty assessments refer to an individual's dependency on others for support with daily care needs and personal care. Similarly, the assessment of functional status often includes quality of life outcomes, which are known to vary considerably among autistic people but may also be broadly underestimated because of a reliance on 'neurotypical' indicators of well-being.⁵¹

In light of these concerns—and in response to challenges by advocacy groups and a proposed judicial review^{52 53}—on 25 March 2020, the UK National Institute for Health and Care Excellence amended their recommendations to specify that frailty assessments should not be used for younger people or autistic people and those with intellectual disability.^{54 55} They also added weblinks to ethical guidance from medical associations (9 April 2020) and stated that—where they are appropriate—frailty assessments should be recorded in the patient's medical record for transparency (29 April 2020). Similar clarifications on the lack of suitability of frailty assessment for those with intellectual disability have been published in the Netherlands.^{56 57} Nevertheless, such measures to prevent the misapplication of frailty assessments to autistic people have not been implemented systematically across European countries.

Moreover, the Working Group of Bioethics of the Spanish Society of Intensive, Critical Medicine and Coronary Units published triage guidance that explicitly specifies 'severe baseline cognitive impairment' as an exclusion criterion for ICU care.⁵⁸ This recommendation is based on previous advice published in 2010 by the European Society of Intensive Care Medicine Task Force for ICU triage during an influenza epidemic, further specifying the exclusion of 'a patient who is unable to perform activities of daily living due to cognitive impairment or is institutionalised due to cognitive impairment'.^{59 60} Similar guidance from the COVID-19 Paris region recommends attention to a patient's previous condition, including neurocognitive status—mildly or severely impaired cognitive functions.⁴⁴

These criteria (and ambiguity in their intended application to real-world clinical practice) plainly increase the

Table 1 COVID-19 triage ethical guidance, published per country, with description of references to frailty, disability, equity and other relevant information

	Austria	Belgium	France	Germany	Greece	Ireland	Italy
Source(s)	Secretariat of the Bioethics Commission, Vienna; Austrian Society for Anaesthesiology, Resuscitation and Intensive Care	Belgian Society of Emergency and Disaster Medicine and the Belgian Resuscitation Council; Ethical Committee Care UZ Leuven	Azoulay <i>et al</i> ¹⁴ ; Comité Consultatif National d'Ethique	German Interdisciplinary Association for Intensive Care and Emergency Medicine	WHO Regional Office for Europe	Department of Health	Italian Society of Anaesthesia, Analgesia, Resuscitation and Intensive Care
Date of publication	31 March 2020; 17 March 2020	22 March 2020; 17 March 2020	5 June 2020; 13 March 2020	17 April 2020	August 2017*	27 March 2020	16 March 2020
'Frailty'	<ul style="list-style-type: none"> ▲ Short-term prognosis using clinical risk assessment (COVID-19 severity; chronic disease/ comorbidity, physical reserves) 	<ul style="list-style-type: none"> ▲ Short-term prognosis and 'good functional outcome' using clinical frailty scale (severe comorbidity, chronic low quality of life, reduced cognition in elderly patients) 	<ul style="list-style-type: none"> ▲ Baseline condition and frailty score (COVID-19 severity, age, comorbidities, neurocognitive status) 	<ul style="list-style-type: none"> ▲ Short-term prognosis and clinical frailty scale (COVID-19 severity, comorbidities if relevant to current illness) 	<ul style="list-style-type: none"> ▲ No unified national triage system 	<ul style="list-style-type: none"> ▲ Short-term prognosis and premorbid and long-term functional health status (COVID-19 severity, comorbidities, frailty independent of age) 	<ul style="list-style-type: none"> ▲ Short-term prognosis, life expectancy and functional status 'Clinical suitability' (COVID-19 severity, comorbidities)
Disability	<ul style="list-style-type: none"> ▲ Special support/ resources for those with disability to ensure equal access and life chances 	<ul style="list-style-type: none"> ▲ None 	<ul style="list-style-type: none"> ▲ Notes that prioritising greater life expectancy could negatively impact those with disabilities 	<ul style="list-style-type: none"> ▲ No exclusion on the basis of underlying illnesses/ disabilities 	<ul style="list-style-type: none"> ▲ No unified national triage system 	<ul style="list-style-type: none"> ▲ None (though no single factor should be used as exclusion criteria) 	<ul style="list-style-type: none"> ▲ None
Equity	<ul style="list-style-type: none"> ▲ No exclusion based on non-medical criteria (including age, quality of life) 	<ul style="list-style-type: none"> ▲ Each individual should have access to same current standard of care or 'the best possible spread ... to the maximum amount of people' 	<ul style="list-style-type: none"> ▲ Value of each individual recognised as absolute 	<ul style="list-style-type: none"> ▲ All individuals considered equally and according to same criteria 	<ul style="list-style-type: none"> ▲ No unified national triage system 	<ul style="list-style-type: none"> ▲ Recognises the moral equality of all people ▲ Equal access to/chance of benefiting from healthcare 	<ul style="list-style-type: none"> ▲ Allocation criteria apply to all intensive care patients

Continued

Table 1 Continued

	Austria	Belgium	France	Germany	Greece	Ireland	Italy
Other	<ul style="list-style-type: none"> ▲ Consider the will of the individual ▲ Transparency in decision making ▲ Involve local ethics advisory service 	<ul style="list-style-type: none"> ▲ Consider the will of the individual ▲ Transparency in documenting decision making ▲ Triage informed by expert team 	<ul style="list-style-type: none"> ▲ Consider the will of the individual ▲ Transparency in documenting decision making ▲ Recommends strategies to reduce stigmatisation of groups facing social inequalities ▲ Involve local ethics advisory service 	<ul style="list-style-type: none"> ▲ Consider the will of the individual ▲ Transparency to patients in decision making ▲ Involve local ethics advisory service 	<ul style="list-style-type: none"> ▲ No unified national triage system 	<ul style="list-style-type: none"> ▲ Consider the will of the individual ▲ Transparency to patients and in documenting decision making ▲ Involve stakeholders in preparedness planning 	<ul style="list-style-type: none"> ▲ Consider the will of the individual ▲ Transparency to patients in decision making ▲ Second opinion useful for difficult cases ▲ Flexible/eligible for local adaptation
Source	Commission Nationale d'Éthique	The Netherlands Royal Dutch Medical Association	Poland Polish Society of Anaesthesiology and Intensive Therapy	Portugal National Council of Ethics for the Life Sciences	Spain Spanish Society of Intensive Critical Medicine and Coronary Units	Switzerland Swiss Academy of Medical Sciences	UK National Institute for Health and Care Excellence; British Medical Association; Royal College of Physicians
Date of publication	31 March 2020	16 June 2020	October 2012*	3 April 2020	21 March 2020	24 March 2020	29 April 2020; April 2020; 2 April 2020
Frailty	<ul style="list-style-type: none"> ▲ Short/medium term prognosis, general health 	<ul style="list-style-type: none"> ▲ Short-term prognosis with clinical frailty score (including recovery time) <i>but</i> do not exclude ID/physical disability based on daily support needs 	<ul style="list-style-type: none"> ▲ Short-term prognosis ▲ Chronic, severe, end-of-life comorbid illness 	<ul style="list-style-type: none"> ▲ None 	<ul style="list-style-type: none"> ▲ Short-term prognosis ▲ Chronic, severe, end-of-life comorbid illness 	<ul style="list-style-type: none"> ▲ Short-term prognosis and perceived benefit of intensive care ▲ Chronic, severe, end-of-life comorbid illness 	<ul style="list-style-type: none"> ▲ Short-term prognosis with clinical frailty score (comorbidities, benefit vs risk, quality of life) <i>but</i> should not be used for younger people, those with stable/chronic disabilities, autism/ID

Continued

Table 1 Continued

	Austria	Belgium	France	Germany	Greece	Ireland	Italy
Disability	<ul style="list-style-type: none"> ▲ Discrimination based on disability absolutely prohibited 	<ul style="list-style-type: none"> ▲ Creating capacity for care in neurodevelopmental/residential care settings ▲ Should not consider 'mental/physical limitation', or prior quality of life 	<ul style="list-style-type: none"> ▲ None 	<ul style="list-style-type: none"> ▲ 'Special attention' to vulnerable groups ▲ Avoid inequalities in access to diagnostics/treatments (eg, for those with chronic conditions) 	<ul style="list-style-type: none"> ▲ Exclude 'severe baseline cognitive impairment' 	<ul style="list-style-type: none"> ▲ Discrimination based on chronic disability precluded 	<ul style="list-style-type: none"> ▲ Duty to not disadvantage one group disproportionately (eg, disability) ▲ Caution indirect discrimination, for example, 'first come first served'/'capacity to benefit quickly' may disadvantage those with disabilities
Equity	<ul style="list-style-type: none"> ▲ No exclusion based on non-medical criteria ▲ Value of each individual recognised as absolute ▲ All patients treated fairly and equally 	<ul style="list-style-type: none"> ▲ Allocation criteria apply to all intensive care patients 	<ul style="list-style-type: none"> ▲ None 	<ul style="list-style-type: none"> ▲ Value of each individual recognised as absolute 	<ul style="list-style-type: none"> ▲ Selection criteria must be equitably applied for all who would benefit from ICU 	<ul style="list-style-type: none"> ▲ Equity crucial as recognised principle of medical ethics 	<ul style="list-style-type: none"> ▲ Each individual matters equally; equal chance of benefiting from resources should mean equal chance of receiving them
Other	<ul style="list-style-type: none"> ▲ Consider the will of the individual ▲ Transparency to patients and in documenting decision making ▲ Involve local ethics advisory service 	<ul style="list-style-type: none"> ▲ Transparency to patients and in documenting decision making ▲ 'The right care in the right place' (eg, consider home treatment) ▲ Triage informed by expert team 	<ul style="list-style-type: none"> ▲ Focus on order of medical prioritisation, rather than inclusion/exclusion criteria 	<ul style="list-style-type: none"> ▲ Transparency to patients and public in decision making ▲ Remove decision making responsibility from individual care providers ▲ Case-by-case decision making 	<ul style="list-style-type: none"> ▲ Consider the will of the individual ▲ Transparency to patients and in documenting decision making ▲ Involve local ethics advisory service ▲ Exclude those who need resources that cannot be provided 	<ul style="list-style-type: none"> ▲ Consider the will of the individual ▲ Transparency in documenting decision making ▲ Triage informed by expert team 	<ul style="list-style-type: none"> ▲ Consider the will of the individual ▲ Transparency to patients and in documenting decision making ▲ Involve local ethics advisory service ▲ Flexibility in adaptable circumstances

Malta is not included because no publicly available triage recommendations or documentation were identified.

*Current COVID-19 specific triage protocols were not identified, however existing information was available about allocation of resources in the case of shortages. ID, intellectual disability.



potential for discriminatory exclusion of autistic people, especially those with co-occurring intellectual disability, and are incompatible with international human rights laws (also emphasised by Spanish reports^{61 62}); yet, they may be informing clinical decision making.⁶³

Access to existing health and social care services

Overall, our review would suggest that the impact of COVID-19 has emphasised longstanding pressures on health and social care systems across Europe and pre-existing healthcare inequalities for autistic people. The first trend observed across all regions reviewed has been the abrupt interruption of usual social support and intervention services to prevent infection spread. While an important safety precaution, without appropriate mitigation measures in place, for some individuals, services have ceased altogether.⁶⁴

Usual health and social care services for autistic people have been particularly impacted in three key areas. First, many services were already stretched in non-pandemic times, including autism diagnostic services, for which average waiting times can be well over a year (a maximum of 13 weeks is recommended by the UK National Institute for Health and Care Excellence).⁶⁵ Considered ‘non-essential’ in light of the COVID-19 pandemic, cancelled or postponed diagnostic appointments may further delay autistic people accessing needs-based support (eg, mental health interventions), which could be contingent on receiving a formal diagnosis.

Second, many community-based services across Europe (eg, day services, workshops, supported employment) are provided by the private sector and non-profit organisations. These organisations have reported experiencing acute financial instability due to COVID-19⁶⁶ and are not always eligible to claim reimbursement for appointments that have been shifted to online delivery (though see flexible legislation from Belgium),⁶⁷ meaning some have been forced to close completely.⁶⁸ As a result, for some autistic people, relatives and other caregivers are currently the only available support people.

For those living in residential care settings, with low capacity for testing and PPE provisions, restrictions have been imposed on visitation from relatives or other caregivers. These restrictions may include a complete ban on visitation, limits on the number of visitors and/or time limits on visitation.^{35 69–71} These measures are designed to prevent infection spread in ‘high risk’ long-term care facilities. However, loss of contact with relatives or caregivers (also constituting a change in routine) could cause distress for autistic people and increase uncertainty and loneliness. Consequently, necessary restrictions on visitation to residential care settings must be balanced with flexible options for alternative communication, such as regular and consistent access to video or telephone contact⁷²—though it should be acknowledged that these options are not sufficient or appropriate for all individuals.

Finally, for those receiving community-based care, we also identified evidence from the UK of ‘easements’ to publicly funded adult social care in response to COVID-19.⁷³ These easements were introduced to relieve pressure on social care services and assist with prioritising support for those in highest need, by reducing the duty to carry out detailed assessments of individual care and support or financial needs, and reducing the duty to prepare or review individual care and support plans. We identified no published evidence to date that any local authorities in England have yet exercised social care easements.⁷⁴ Nevertheless, it is essential that this situation continues to be closely monitored to ensure that those in need receive adequate support, particularly given the significant lack of reliable data gathered on community-based health and social care provision across Europe.⁷⁵

Lived experiences from the autism community (April–May 2020)

Accessibility of COVID-19 testing and screening

Corresponding to findings from our policy review—detailed above—the results from Autism-Europe’s survey of autistic people and caregivers (see [table 2](#)) also indicated that despite being considered at increased risk of poor outcomes from COVID-19, there was a lack of accessibility to COVID-19 testing.

For instance, 26% (n=327) of autistic people represented in Autism-Europe’s survey were reported to be considered at high risk from COVID-19. Nevertheless, of the 5% of autistic people who accessed a COVID-19 test, 25% (n=13) felt they did not receive, or were unsure whether they had received, adequate accessible information about the test procedure ([table 2](#)). Furthermore, only 39% (n=22) were provided with autism-specific reasonable adjustments (eg, allowed to be accompanied by a support person; tested in a quiet space). These issues were particularly emphasised by the report of one parent of a child with autism, who commented:

I wanted to get my son tested but there was no way to get this done without sedating him. This was not provided by the doctors and it was such a traumatic experience ended up [sic] not doing the test after 1.5 hours of trying and quarantined instead for 2 weeks.

Access to treatment, hospitalisation and intensive care

Additionally, survey data showed that a proportion of autistic people also experienced difficulties accessing COVID-19 outpatient and inpatient treatment services.

Of the 2% (n=28) of autistic people captured by Autism-Europe’s survey who required COVID-19 treatment, around half reported access difficulties (n=12), mostly accounted for by inaccessibility of the process of contacting healthcare providers (n=9; for example, contact by telephone was required):

Similarly, communication difficulties can represent a major barrier for receiving quality inpatient treatment

Table 2 Autism-Europe survey responses for access to COVID-19 health and social care services for people with autism. Data are numbers (%)

	Overall response			Autistic person response			Caregiver response		
	Yes	No	Unsure	Yes	No	Unsure	Yes	No	Unsure
High COVID-19 risk (autistic person)	327 (26)	795 (63)	133 (11)	90 (27)	213 (63)	33 (10)	237 (26)	582 (63)	100 (11)
Tested for COVID-19	56 (5)	1095 (95)	1 (0)	13 (4)	295 (96)	0 (0)	43 (5)	800 (95)	1 (0)
Accessible information—COVID-19 test	40 (76)	10 (19)	3 (6)	7 (58)	4 (33)	1 (8)	33 (80)	6 (15)	2 (5)
Reasonable adjustments—COVID-19 test	22 (39)	31 (54)	4 (7)	6 (30)	11 (55)	3 (15)	16 (43)	20 (54)	1 (3)
Required COVID-19 treatment	28 (2)	1112 (96)	13 (1)	7 (2)	296 (96)	5 (2)	21 (2)	816 (97)	8 (1)
Difficulties accessing treatment	12 (43)	15 (54)	1 (4)	5 (71)	2 (29)	0 (0)	7 (33)	13 (62)	1 (5)
Difficulties contacting treatment provider	9 (75)	3 (25)	0 (0)	3 (60)	2 (40)	0 (0%)	6 (86)	1 (14)	0 (0)
Require daily or occasional support	882 (68)	398 (31)	21 (2)	184 (53)	146 (42)	16 (5)	698 (73)	252 (26)	5 (1)
Usual daily support stopped	595 (71)	211 (25)	31 (4)	73 (42)	84 (48)	17 (10)	522 (79)	127 (19)	14 (2)
High COVID-19 risk (support person)	279 (33)	409 (49)	149 (18)	50 (29)	94 (54)	30 (17)	229 (35)	315 (48)	119 (18)
Second support person available	247 (30)	523 (63)	67 (8)	44 (25)	107 (61)	23 (13)	203 (31)	416 (63)	44 (7)
Accessible information—COVID-19 public health	421 (35)	557 (46)	234 (19)	119 (36)	117 (35)	94 (28)	302 (34)	440 (50)	140 (16)

in general hospital settings, as noted by one person with autism:

I had to be hospitalised with acute abdominal cramps. On the spot, the nursing staff took my temperature and, worried, they did not know what to do: whether to put me in a separate room, because I could have COVID-19, or not. I was in the Emergency Room for 6 hours, the doctors deliberated my case, and in the end I was not tested. During the whole process, I was mute, paralysed. So I wonder if there is a way to communicate with the medical professionals about everyone's situation without adding to the medical professionals' workload.

Moreover, concerns regarding inequalities in access to COVID-19 services could pose a barrier for seeking treatment, with one autistic Autism-Europe survey respondent revealing:

I am also afraid that as a mentally impaired [sic] recipient of a disability pension, during possible triage I will be rated worse than those capable of working of the same age (ableism) should there be shortages of medical care.

This comment highlights the importance of ensuring that public health information is made accessible for the autism community, with 65% (n=791) of Autism-Europe

survey respondents being unaware or unsure of accessible information about current COVID-19 measures.

Access to existing health and social care services

Finally, reflecting the impact of the abrupt interruption of usual social support and intervention services on autistic people, 71% (n=595) of Autism-Europe survey respondents included in this review indicated that their usual support services had been stopped due to COVID-19. This is notable given that approximately one third of those surveyed indicated that they required daily support (35%; n=451) and one third required occasional support with daily life activities (33%; n=431).

In addition, 33% (n=279) of Autism-Europe survey respondents stated that their usual support person was also at increased risk of COVID-19% and 63% (n=523) reported they did not have access to another support person if their usual caregiver became infected.

DISCUSSION

Summary of key findings and recommendations

We reviewed COVID-19 health and social care access for autistic people across 15 European member states, based on published policies or guidelines and results from a large-scale survey of over 1300 autistic people and caregivers. Our findings highlighted several issues regarding

COVID-19 service access for autistic people that require rapid consideration, in terms of testing and screening; accessibility of treatment, hospitalisation and ICU care; and changes to standard health and social care provision.

Specifically, we identified (1) failure to prioritise and provide adequate adaptations to promote access to testing, despite elevated risk of severe COVID-19 disease due to commonly co-occurring physical health problems; (2) barriers for accessing treatment and hospitalisation (eg, alternative communication needs) and ICU triage protocols that directly or indirectly (ie, through their ambiguity) discriminate against those with additional needs; and (3) abrupt interruptions to existing service provision (eg, mental health or community-based services) without appropriate mitigation measures, further exacerbated by longstanding pressures on health and social care. Considering these issues, we formulated a set of recommendations for policy and clinical practice to improve health and social care access for autistic people in pandemic situations and other public health emergencies (box 1).

Enhancing accessibility of COVID-19 testing and screening

As outlined above, our first key finding was a failure to prioritise and systematically provide adequate adaptations to promote access to testing for autistic people. COVID-19 strategies published by the World Health Organization and European Commission emphasise the critical importance of testing people with suspected COVID-19 so that people with confirmed infection can be isolated and their close contacts traced.^{76 77} COVID-19 testing strategies and capacity have varied among European countries. However, broadly, infrastructure limitations (eg, manual processing of test data, financial) and supply shortages mean that testing capacity has fallen below growing demand across the EU.⁷⁸ According to the World Health Organization and European Commission, in the case of insufficient testing capacity, priority groups for rapid testing in EU countries should include those at increased risk of developing severe disease (including acute respiratory illness and elderly populations with chronic health conditions); symptomatic health and social care workers; and those in closed settings, such as residential care homes^{76 79}—criteria highly relevant to a proportion of autistic people.

However, it must be acknowledged that many autistic people experience additional barriers that could increase their risk of poor outcome from COVID-19, which should therefore also be explicitly acknowledged in policy and clinical documentation and guidance. These barriers include atypical symptom presentation (which may partly reflect high comorbidity burden and also lead to relevant comorbid physical health risk factors going undiagnosed), diagnostic overshadowing, and difficulties identifying and describing symptoms (see reviews of interoception difficulties and alexithymia in autism),^{80 81} which could lead to late or missed diagnosis, or misdiagnosis, and difficulties gaining access to appropriate treatments.

Box 1 Recommendations for an aligned European strategy for reducing inequalities in access to health and social care services for autistic people and those with intellectual disability in pandemic situations

Policy recommendations

1. Policy documentation should explicitly outline strategies for promoting equitable access to testing and screening for autistic people, including clinical guidance on identifying symptoms (given evidence for atypical symptom presentation, diagnostic overshadowing and high comorbidity burden), providing accessible inpatient and outpatient care and enhancing the accessibility of testing procedures by providing preparatory materials and considering flexible test procedures (eg, saliva vs swab testing). Autistic people with physical health comorbidities and those living in 'high risk' settings for disease transmission, such as residential care and supported accommodation, should be considered for priority access to proactive testing and screening, even when apparently asymptomatic.
2. If hospital admission is necessary, autistic people should receive the necessary accommodations and support to facilitate access to the same resources and standard of care as other individuals. This support may include the development of consistent policies to ensure: accessible information and communication methods; frequent consultation between the individual, their families (if appropriate) and care provider(s); formal guidance and training to support care providers from all specialities; greater flexibility in care provision.
3. Triage protocols across Europe require urgent review and update, in consultation with stakeholders (eg, intensive care and autism communities), to inform an aligned European strategy on the fair allocation of resources in public health emergencies that does not explicitly or inadvertently discriminate against any individual or groups of individuals on the grounds of pre-existing characteristics or difficulties.
4. The impact of COVID-19 on health and social care service provision should be comprehensively reviewed to inform mitigation or contingency plans for the safe and effective delivery of services in the short and longer term. In particular, the collection of high quality and reliable data on health and social care provision will support a targeted approach for identifying (cost-)effective strategies for restructuring and investment in health and social care, likely including greater flexibility in service provision (eg, telehealth, needs vs diagnosis based support) and community based care.

Clinical practice recommendations

1. Mandatory provision of alternative, accessible and easy-read healthcare information and communication toolkits.^{111 112}
2. Mandatory consultation with autistic people to provide prior information about themselves, their preferences and healthcare needs, in case they become unable to communicate on admission to hospital (eg, the COVID-19 'Grab and Go' Guide).¹¹³ This is essential to prevent healthcare decisions being made without the consent of patients and their families, as exemplified by the concerning application of COVID-19 'Do not attempt resuscitation' orders to the notes of some autistic people, without consultation.¹¹⁴
3. Mandatory, regularly updated formal guidelines and training for all healthcare providers, co-developed with autistic people and supported by access to specialist providers like learning disability or psychiatric liaison staff.^{35 63 115}
4. Introducing flexibility to some regulations (if appropriate), such as allowing a caregiver or support person to accompany the individual into hospital, following all necessary infection control procedures

Continued

Box 1 Continued

(already in place in regions of the UK, Germany and the Netherlands, according to clinician reviews) and making reasonable adjustments to ensure this flexibility is fulfilled in real-world clinical settings.

Considering these issues, our first recommendation for an aligned European strategy for responding to pandemic situations is that—in the case of testing shortages—autistic people should be considered for priority access to testing if they are living in ‘high risk’ settings for disease transmission (even when apparently asymptomatic), such as residential care and supported accommodation ([box 1](#)).

To further promote equitable access to testing, it is important to also consider flexible testing methods to remove barriers for autistic people, who often experience sensory sensitivities associated with procedures like swab tests. Currently, if an individual is symptomatic but cannot be tested then good public health practice would be to treat the individual as a suspected case, which could result in enhanced (and potentially unnecessary) restrictions being disproportionately imposed on some groups of individuals with additional needs. Examples of methods for enhancing the accessibility of testing procedures include the provision of high-quality preparatory materials, such as social stories and videos, available in different languages and easy-read formats, to demonstrate the testing procedure in advance (for examples, please see [AsIAM](#)⁸⁷). Moreover, for those who cannot tolerate swab testing, the use of non-invasive saliva sampling could be considered and can be readily performed at home. Of note, the utility of the saliva method for COVID-19 testing has been demonstrated^{82 83} and is already approved by the US Food and Drug Administration, and in use in some European countries, including Germany.

Enhancing access to treatment, hospitalisation and intensive care

Enhancing the accessibility of COVID-19 testing, particularly in cases of shortage, has added potential to reduce the proportion of autistic people who require any treatment, hospitalisation or intensive care by reducing viral transmission. This is significant given that autistic people often have suboptimal experiences of accessing healthcare and hospital admission,^{13–15} and experience higher odds of death in hospital. Furthermore, the resources required to adequately support autistic people during hospitalisation are likely to be considerably stretched in pandemic situations.⁸⁴ There have been (and are currently) concerns across Europe about the ‘surge’ capacity of healthcare systems to cope with acute increases in patients requiring hospital and intensive care beds.⁸⁵

Increasing capacity and investing in resilience planning should be the primary response for ensuring equal access to hospital and intensive care resources, across the population. Nevertheless, it is necessary for formal

guidance to be provided for clinicians on the fair allocation of resources in times of scarcity. For example, officially documented intensive care triage protocols for public health emergencies, combined with designated local ethics panels within healthcare settings, are essential to ensure that individual clinicians are never responsible for taking or implementing triage decisions and to avoid conflicts of interest.^{86 87} On the grounds of fundamental human rights, it is paramount that this guidance does not discriminate against individuals or groups of individuals on any illegitimate grounds, including developmental difference or disability, as highlighted in a recent open letter by the International Disability Alliance^{88–90} and reflected in the ICU triage protocols of eight of the 14 European regions reviewed (please see [table 1](#)).

Consequently, our second set of recommendations relate to proper resourcing and care planning, which must be implemented to support autistic people who develop severe COVID-19 symptoms in general hospital settings ([box 1](#)).

While these recommendations have been specifically applied to supporting the needs of autistic people, it should be emphasised that they may be more broadly beneficial for other groups. For instance, introducing flexibility to regulations may also support individuals with intellectual disability (but not autism), other neurodevelopmental conditions (eg, attention deficit hyperactivity disorder and behavioural problems) and mental health conditions, such as anxiety. Similarly, the provision of accessible healthcare information and communication toolkits would be equally applicable for individuals with sight or hearing loss, or speech and language difficulties.⁹¹

Moreover, our third recommendation is that triage protocols are urgently reviewed and updated, in consultation with stakeholders, to inform an aligned European strategy on the fair allocation of resources in public health emergencies ([box 1](#)). This strategy is essential to prevent the widespread exclusion of autistic people from ICU, to promote better healthcare equality across Europe, and to provide official guidance and support to regions where it is currently unavailable. Joint consultation between ICU clinicians and the autism community could further aid this progress by clarifying the application of triage protocols in everyday clinical practice, reducing the potential for bias to enter into clinical and legislative recommendations, and promoting transparency to ensure that individuals are not deterred from seeking services due to fear of exclusion.

Enhancing access to existing health and social care services

With the proper resourcing and funding of health and social care systems, the prospective need to implement triage protocols is reduced. After the economic crisis of 2008–13, public spending on health slowed or fell across at least 24 European countries, both in absolute terms and as a share of overall government spending.⁹² In addition, there is very little available evidence to suggest

the most (cost-)effective ways to provide social care for autistic people.⁹³

Despite these issues, many non-emergency health and social care services have not altogether ceased as a result of COVID-19, but instead have been shifted from in-person to remote or online delivery (ie, 'telehealth'). The fast implementation of telehealth in response to COVID-19 could have a positive impact on clinical practice in the longer term,^{94 95} particularly for improving accessibility and reducing costs of health and social care services. For instance, one previous systematic review showed that outcomes of telehealth assessment and interventions for autistic people were broadly comparable to face-to-face consultations and superior to comparison groups who received no consultation at all.⁹⁶ Additionally, telehealth may be particularly beneficial for enabling individuals who live in areas with particular service or specialist staff shortages to access high-quality support from elsewhere.⁹⁷ Thus, even prior to COVID-19, telehealth had been identified as a key area for promoting more effective, accessible and resilient European healthcare systems.⁹⁸

However, there is a lack of research about the most effective and appropriate methods for implementing telehealth services that ensure continuity of care, and more data are needed about which in-person services (particularly in the social care domain) are (or are not) conducive for remote implementation. Therefore, to ensure that telehealth fulfils its future positive potential to improve the quality of healthcare for autistic people and those with intellectual disability, more research is required on how it can be implemented in an accessible and personalised way.^{99 100} For instance, the European Disability Forum recommends that all information is provided in plain, easy-to-read language, alternative methods are provided for those who communicate by different means or who do not have access to certain technologies (eg, video, telephone, email/messaging services), and the accessibility needs of different groups (including younger children) are considered—for example, appropriate sign language interpretation or captioning and symbols.¹⁰¹ Some of these recommendations require that the care provider has specialist training on supporting autistic people and those with intellectual disability, and all require future research into their efficacy in everyday clinical practice.

Overall and based on the evidence reported above, our final (and broadest) recommendation is that the impact of COVID-19 on health and social care service provision for autistic people is comprehensively reviewed to inform contingency plans for the safe and effective delivery of services in the short and longer term (**box 1**). This could include a shift to more community-based care and incorporating greater flexibility to ensure that services can quickly adapt to changing circumstances—for example, reducing the demand for a formal diagnosis of autism as a prerequisite for accessing needs-based support. Furthermore, there is a significant need for high-quality and reliable data⁷⁵ to identify key areas for targeted restructuring and investment for improving health and social care

provisions (eg, strategies for earlier detection of support needs and early interventions) for autistic people.

Learning from best practice and future directions

Though it is of paramount importance to address the barriers for COVID-19 health and social care services highlighted in this review, it should be noted that we also identified good examples of strategies to support autistic people and those with intellectual disability. Many services and individual professionals have made considerable efforts to continue to support autistic people in these unprecedented times and shown incredible adaptability and innovation. For instance, non-profit organisations across Europe have provided comprehensive and accessible online toolkits to support families and regular expert webinars on topics like mental health and coping with uncertainty.^{23 102 103} Additionally, some healthcare providers have implemented 24/7 telehealth services and live-in residential care.⁶³ Several reasonable adjustments have also been made across Europe for autistic people, including exceptions on wearing face masks in public and allowing increased daily exercise during lockdown periods. Finally, in response to lobbying by non-profit organisations, new and amended guidance on supporting autistic people has started to be released, which we aim to complement and accelerate with the current report.

It is clear there are many additional issues facing autistic people in relation to COVID-19, which were beyond the scope of the current review, but must be investigated in future research. These issues include the impact of isolation; changes in education and employment; public understanding of adjustments to regulations for autistic people; and, now, how earlier policies have impacted on the accessibility of vaccination programmes and strategies. In particular, the mental and physical health impacts of COVID-19 should be assessed, given high reported rates of pandemic-related stressors among families with a child with autism,^{104–106} and possible long-term mental and physical health implications of COVID-19 infection.^{107 108} Furthermore, longitudinal data on health and social care access and the impact of disruptions to education and community facilities before, during and after the COVID-19 pandemic may reveal critical areas for addressing future policy and practice.

Strengths and limitations

This review represents the first comprehensive analysis of COVID-19 health and social care access for autistic people across 15 European countries, also capturing the lived experiences of over 1300 individuals from the autism community. Nevertheless, our findings must be considered in the context of the following limitations. First, it was not possible to collect information from all European countries in this study and there were important regional differences within countries that were included, in terms of COVID-19 policies and public health strategies. As a result, the reported findings represent an overview, rather than a nuanced analysis, of the current

situation and approaches of each country. This limitation was somewhat unavoidable, given the constantly evolving situation, in which new sources and data were iteratively published and amended between March and July 2020. Moreover, European countries worst hit by the COVID-19 pandemic (eg, the UK, Spain, Italy) had the most available resources and data, thus making them more eligible for inclusion. Despite this, evidence collated from countries where resources and data were freely accessible, combined with lived experiences from the autism community through survey data, were paramount for informing our recommendations for an aligned European strategy for responding to pandemic situations.

Second, with the exception of triage protocols, we were largely unable to make direct comparisons between countries because each country has different health and social care systems. For instance, some health systems are free to the user, whereas in others a large proportion of the population have private health insurance.^{109 110} Similarly, the proportion of social care services provided by the government, non-profit and private organisations varies across Europe.¹¹⁰ To capture COVID-19 health and social care access, systematically adjusted for health system variability, it would be necessary to gather long-term data (eg, insurance data) before, during and after the COVID-19 pandemic. However, in this study our primary aim was to collate current policies and guidelines to inform rapid recommendations for improving COVID-19 service access for autistic people prior to potential future peaks of the virus.

Finally, as with the policy review, response rates from the Autism-Europe survey were somewhat biased toward those countries particularly impacted by COVID-19, such as Italy and Spain. Response biases may also have been introduced by the convenience sampling method, the snapshot of time within which the survey was administered and the informant—with the majority of included respondents (~73%) being caregivers, who may therefore be more likely to report on behalf of autistic people with particularly high support needs, including children and those with co-occurring intellectual disability (although it was not possible to confirm this on the basis of the available data). Despite this limitation, the inclusion of data on the lived experiences from the autism community was crucial to demonstrate how policy and guidelines were being reflected in real-world practice and to ensure these experiences were reflected in recommendations for enhancing accessibility of services for autistic people.

CONCLUSIONS

The global COVID-19 pandemic has had an unprecedented impact on European health and social care systems, with supply chains and services forced to adapt rapidly to increased demand. In this review, we identified several significant barriers in access to COVID-19 services for autistic people, despite their increased risk of severe illness and mortality due to factors such as frequently

co-occurring physical health conditions, difficulties with symptom identification, and living in residential care. Barriers for accessing COVID-19 services included (1) a lack of accessibility to testing, including difficulties tolerating swab procedures; (2) lack of access to outpatient and inpatient treatment, largely due to differences in communication needs (eg, difficulty using telephone); (3) ICU triage protocols that may directly or indirectly exclude individuals from lifesaving treatment; and (4) abrupt interruptions to standard health and social care, including mental health interventions. Considering the evidence reported, we provide specific recommendations for an aligned European strategy to reduce health and social care inequalities in public health emergencies (box 1), which require particularly urgent consideration to enhance the future care of autistic people both during and beyond the pandemic.

Author affiliations

¹Department of Forensic and Neurodevelopmental Sciences, King's College London, London, UK

²Department of Psychology, King's College London, London, UK

³Department of Applied Psychology: Health, Development, Enhancement, and Intervention, University of Vienna, Vienna, Austria

⁴Autism Research Centre, Department of Psychiatry, University of Cambridge, Cambridge, UK

⁵Autism Europe, Brussels, Belgium

⁶South London and Maudsley NHS Foundation Trust, (SLaM), London, UK

⁷Centre for Brain and Cognitive Development, Birkbeck University of London, London, UK

⁸Autistica, London, UK

⁹Department of Anaesthesia, Our Lady's Hospital, Navan, Meath, Ireland

¹⁰Department of Tropical and Parasitic Diseases, Medical University of Gdansk, Gdansk, Poland

¹¹Department of Child & Adolescent Psychiatry, King's College London, London, UK

¹²Donders Institute for Brain, Cognition and Behavior, Department of Cognitive Neuroscience, Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands

¹³Karakter Child and Adolescent Psychiatry, University Center, Nijmegen, The Netherlands

¹⁴Discipline of Psychiatry, Trinity Translational Medicine Institute, Trinity College, Dublin, Ireland

¹⁵Sackler Institute for Translational Neurodevelopment, King's College London, London, UK

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ORCID iDs

Julian Tillmann <http://orcid.org/0000-0001-9574-9855>

Tony Charman <http://orcid.org/0000-0003-1993-6549>

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