COVID-19 health and social care access for autistic people and individuals with intellectual disability: A European policy review.

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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 groups, including autistic people/ those with intellectual disability (ID), may become excluded from services.

Methods: We reviewed policies from 15 European member states, published March-July 2020, pertaining to: 1) accessibility of COVID-19 testing; 2) provisions for treatment, hospitalisation and intensive care units (ICU); and 3) changes to standard health and social care. In parallel, we analysed survey data on the lived experiences of 1,301 autistic people and caregivers.

Results: Autistic people/ those with ID experienced significant barriers accessing COVID-19 services. First, despite these groups being at elevated risk for severe illness due to co-morbid health conditions, there was a lack of access to 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 (directly or indirectly) resulted in discriminatory exclusion from lifesaving treatments. Last, interruptions to standard health and social care left over 70% of autistic people without everyday support.

Conclusions: The COVID-19 pandemic has further emphasised healthcare inequalities for autistic people/ those with ID, likely contributing to disproportionate increases in morbidity and mortality in these groups. Current policies and guidelines regarding the accessibility of COVID-19 services require urgent revision to prevent the widespread exclusion of autistic

people and those with ID from services, which represents a violation of international human rights law.

Introduction

Over 5 million SARS-CoV2 (hereafter COVID-19) cases and 200,000 coronavirus-related deaths had been reported in Europe by 21st September 2020, making it one of the worst hit regions worldwide (1). During global viral pandemics and public health emergencies, like COVID-19, there is a significant risk that overwhelming and sustained demand for healthcare resources may exceed the capacity of healthcare systems (2,3). Consequently, mitigation measures to reduce pressures on health and social care systems have been implemented in many regions, including strict national lockdown policies (i.e. restrictions on movement) to slow virus transmission (4). Nevertheless, within just one 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/ 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 and those with intellectual disability (ID) - may be particularly vulnerable to being excluded from services, support and treatment in pandemic situations (6).

Reports from the US already indicate 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 (7). Furthermore, COVID-19 may disproportionately impact autistic people (at least 32% of whom have co-occurring ID; 8) due to elevated physical health comorbidities and existing healthcare inequalities. For example, physical health conditions are experienced at substantially higher rates by autistic people, as

compared to the general population, including conditions associated with high risk of severe illness from COVID-19 (e.g. cardiovascular/ immune conditions, diabetes, obesity; 9–12). In addition, autistic people experience numerous existing barriers to accessing general healthcare, which may also increase their risk of being excluded from COVID-19 services. These barriers include: communication difficulties, which can lead to misunderstandings by healthcare providers and reduced involvement of patients in healthcare decision making; sensory sensitivities (e.g. around physical examinations); difficulties identifying and/ or describing pains and symptoms and inconsistent specialist clinician training, awareness and knowledge about autism and ID (13–16). Health providers may also misattribute COVID-19 symptoms to existing medical, mental health or behavioural problems (‘diagnostic overshadowing’), increasing risk for severe disease due to missed or late diagnosis (17).

Difficulties and delays in accessing COVID-19 services may partly explain why the UK death rate of people with ID (some of whom will also be autistic) increased by 134% in the period mid-April to May 2019 vs. 2020 - notably higher than in the total population, where deaths increased by 80% (18,19). Additionally, at least 40-60% of confirmed COVID-19 deaths across European countries with community transmission are believed to have occurred in long-term care facilities (20) - a proportion of which offer residential care for autistic people/ those with ID. Of further concern, although guidelines around COVID-19 management and ID were released by the World Health Organisation in March 2020 (21) and more detailed information has since been published by charities and clinical research teams (22–25), the extent to which these recommendations were distributed and implemented within national policies across Europe is unclear.

Hence, we collated and reviewed regional/ national policies and guidelines from 15 European member states, covering three priority areas: 1) accessibility of COVID-19 testing; 2) provisions for treatment, hospitalisation and access to Intensive Care Units (ICU); and 3)

changes to standard health and social care. We considered whether current guidelines (directly or indirectly) discriminate against (or are protective for) autistic people and those with ID. 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 their 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 1,301 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 Supplementary Table 1.

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 $N=165$; 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 $N=1$.

Materials and procedures

Review of European COVID-19 policy/ guidelines

COVID-19 related policies and guidelines from 15 European countries (Figure 1) were assessed using a common review template (please see Supplementary Material 1), indexing three priority areas – accessibility of testing/ screening; provisions for 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 (i.e. online/ open access) and

published between March and July 2020. A full list of included documents is provided in Supplementary 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 5 representatives from the autism community. In addition, documents were reviewed 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 ID 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/ guidelines. We excluded respondents who were not autistic people, nor relatives/ caregivers (as the identity of ‘other’ respondents was not clearly defined) and those who opened but did not answer survey questions. This resulted in a final sample of 1,301, including 346 autistic people and 955 caregivers.

Survey items requested from Autism-Europe for the purpose of this review are documented in Supplementary Table 3. The survey was disseminated between April 7th and May 31st 2020, in ten languages. 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 (please see Table 3), and gave written permission for the publication of their anonymised quotations.

Results

Accessibility of COVID-19 testing

Access to COVID-19 tests

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, Netherlands and Belgium (26–28) - a large proportion of autistic people and those with ID meet criteria for priority COVID-19 testing on at least two accounts. First, autistic people and those with ID experience high rates of physical health comorbidities that are associated with elevated risk of developing severe disease on contracting COVID-19, including cardiovascular/ respiratory illness, autoimmune conditions, diabetes, obesity and hypertension (9–12). This was also reflected in Autism-Europe survey responses, where 26.1% ($N=327$) of autistic people reported that they were considered to be at high risk from COVID-19 – slightly higher than average estimates for the general population (~22%; 29).

Second, approximately 5-25% of autistic people live in residential care and up to a further 27% in supported accommodation, with upper bound estimates referring to those with ID (30). This is notable, as the transmission rate of COVID-19 in residential care settings is high, due to factors like: 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 (e.g. if residents require personal care; 31,32).

Despite evidence that autistic people and those with ID may be at increased risk of poor outcomes from COVID-19, our review indicated that these groups 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 symptoms (33). In the Republic of Ireland and UK, care home residents (including asymptomatic cases) were not officially added to the list for priority access to COVID testing until 17th and 29th April 2020, respectively – at least two months after the first confirmed COVID-19 cases in these regions (27,34). Similarly, other countries that did not initially do so, now identify individuals in residential care settings as priority for testing - including the Netherlands and Belgium (26,28).

However, we did not identify any additional published guidance, nor strategies, for prioritising autistic people and those with ID living in ‘high risk’ settings for access to testing across the other regions reviewed in this study; and those living in supported accommodation and the community remain particularly overlooked.

Tolerability of COVID-19 test procedures

In addition to difficulties accessing COVID-19 tests, the tolerability of test procedures for autistic people and those with ID must be considered. For example, sensory sensitivities are highly associated with autism (35,36) and COVID-19 diagnostic tests frequently involve nasal/ throat swabs or aspiration (37). Some test procedures also require travel to an unfamiliar location, which can present difficulties for some individuals around uncertainty and change in routine.

Evidence for the challenges experienced by autistic people during testing for COVID-19 was captured by Autism-Europe’s survey, from which 4.9% ($N=56$) reported accessing a

test. Of those who accessed a test, 24.5% ($N=13$) felt they did not receive, or were unsure whether they had received, adequate accessible information about the test procedure (Table 1).

Only 38.6% ($N=22$) were provided with autism-specific reasonable adjustments (e.g. 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 an autistic child, 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 h[ou]rs of trying and quarantined instead for 2 weeks.”

Table 1.

Autism-Europe survey responses for access to COVID-19 health and social care services.

	Response		
	Y	N	Unsure
High COVID-19 risk (autistic person)	327 (26.1%)	795 (63.3%)	133 (10.6%)
Tested for COVID-19	56 (4.9%)	1095 (95.1%)	1 (0.09%)
Accessible information - COVID-19 test	40 (75.5%)	10 (18.9%)	3 (5.7%)
Reasonable adjustments - COVID-19 test	22 (38.6%)	31 (54.4%)	4 (7.0%)
Required COVID-19 treatment	28 (2.4%)	1112 (96.4%)	13 (1.1%)
Difficulties accessing treatment	12 (42.9%)	15 (53.6%)	1 (3.6%)
Difficulties contacting treatment provider	9 (75.0%)	3 (25.0%)	0 (0.0%)
Require daily/ occasional support	882 (67.8%)	398 (30.6%)	21 (1.6%)
Usual daily support stopped	595 (71.1%)	211 (25.2%)	31 (3.7%)
High COVID-19 risk (support person)	279 (33.3%)	409 (48.9%)	149 (17.8%)
Second support person available	247 (29.5%)	523 (62.5%)	67 (8.0%)
Accessible information - COVID-19 public health	421 (34.7%)	557 (46.0%)	234 (19.3%)

Access to treatment, hospitalisation and intensive care

Access to treatment/ hospitalisation

Next, we reviewed current recommendations for the admission of autistic people and those with ID for COVID-19 treatment and hospitalisation. Findings first highlighted that guidance from several European regions, including Belgium, Italy and the Netherlands, currently recommends that autistic people and those with behavioural problems are treated for COVID-19 within designated neurodevelopmental/ neuropsychiatric pathways, rather than general hospital settings (38,39).

This approach may have some benefit in providing 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 (e.g. allowing visitation by a caregiver or support person, with appropriate hygiene measures in place). Indeed, of the 2.4% ($N=28$) of Autism-Europe survey respondents who required COVID-19 treatment, around half reported access difficulties ($N=12$) – mostly accounted for by inaccessibility of the process of contacting healthcare providers ($N=9$; e.g. contact by telephone was required).

Similarly, communication difficulties can represent a major barrier for receiving quality inpatient treatment in general hospital settings, as noted by one autistic person:

“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 six 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 professions workload.”

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*” (40). Examples of concerns regarding COVID-19 care provision in neurodevelopmental/ psychiatric pathways include shortages of staff with both medical/ surgical and psychiatric expertise and experience. In addition, there are added challenges for controlling infection spread in neurodevelopmental/ 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 (41).

Access to intensive care

Moreover, our review also 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 2).

For example, several European countries with published triage protocols recommend the consideration of ‘functional status’ and/ or use of ‘frailty assessments’ – including the UK, Republic of Ireland, France, Netherlands, Italy, Belgium, Austria and Germany (42–50). These assessments were originally designed with reference to elderly populations, to indicate individuals with very poor prognosis for recovery from their current illness (51). 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/ those with ID may be conflated with ‘frailty’ (40,52,53). 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 between autistic people, but may also be broadly underestimated due to a reliance on ‘neurotypical’ indicators of wellbeing (54–56).

In light of these concerns - and in response to challenges by advocacy groups and a proposed judicial review (57,58) - on 25th March 2020, the UK National Institute of Health and Care Excellence amended their recommendations to specify that frailty assessments should not be used for younger people or autistic people/ those with ID (59,60). They also added weblinks to ethical guidance from medical associations (9th April 2020) and stated that frailty assessments should be recorded in the patient’s medical record for transparency (29th April 2020). Similar clarifications on the lack of suitability of frailty assessment for those with ID have been published in the Netherlands (61,62). Nevertheless, such measures to prevent the misapplication of frailty assessments to autistic people/ those with ID have not been applied 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 criteria for ICU care (63). This recommendation is based upon 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*” (64,65). 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 (47).

These criteria (and ambiguity in their intended application to real-world clinical practice) plainly increase the potential for discriminatory exclusion of autistic people and

especially individuals with ID, and are incompatible with international human rights laws (also emphasised by 66,67). Yet, they may be informing clinical decision-making (68), 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.”

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 and those with ID.

The first trend observed across all regions reviewed has been the abrupt interruption of usual social support and intervention services. Approximately one-third of Autism Europe survey respondents indicated that they required daily support (34.7%; $N=451$) and one-third occasional support with daily life activities (33.1%; $N=431$). Furthermore, 71.1% ($N=595$) of Autism-Europe survey respondents included in this review indicated that their usual support services had been stopped due to COVID-19. For some individuals, services have ceased altogether (69).

Table 2.

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

	Region						
	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 et al (2020); Comité Consultatif National d'Ethique	German Interdisciplinary Association for Intensive Care and Emergency Medicine	World Health Organisation Regional Office for Europe (2017)	Department of Health	Italian Society of Anaesthesia, Analgesia, Resuscitation and Intensive Care
'Frailty'	- Short-term prognosis using Clinical Risk Assessment (COVID-19 severity, chronic disease/comorbidity, physical reserves).	- Short-term prognosis and 'good functional outcome' using Clinical Frailty Scale (severe comorbidity, chronic low quality of life, reduced cognition in elderly patients).	- Baseline condition and frailty score (COVID-19 severity, age, comorbidities, neurocognitive status).	- Short-term prognosis and clinical frailty scale (COVID-19 severity, comorbidities if relevant to current illness).	- No unified national triage system.	- Short-term prognosis and pre-morbid and long-term functional health status (COVID-19 severity, comorbidities, frailty independent of age).	- Short-term prognosis, life expectancy and functional status. - 'Clinical suitability' (COVID-19 severity, comorbidities).
Disability	- Special support/resources for those with disability to ensure equal access and life chances.	- None.	- Notes that prioritising greater life expectancy could negatively impact those with disabilities.	- No exclusion on the basis of underlying illnesses/disabilities.	- No unified national triage system.	- None (though no single factor should be used as exclusion criteria).	- None.

Equity	- No exclusion based on non-medical criteria (including age, quality of life).	- Each individual should have access to same current standard of care or 'the best possible spread... to the maximum amount of people'.	- Value of each individual recognised as absolute.	- All individuals considered equally and according to same criteria.	- No unified national triage system.	- Recognises the moral equality of all people. - Equal access to/ chance of benefitting from healthcare.	- Allocation criteria apply to all intensive care patients.
Other	- Consider the will of the individual. - Transparency in documenting decision making. - Involve local ethics advisory service.	- Consider the will of the individual. - Transparency in documenting decision making. - Triage informed by expert team.	- 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.	- Consider the will of the individual. - Transparency to patients in decision making. - Involve local ethics advisory service.	- No unified national triage system.	- Consider the will of the individual. - Transparency to patients and in documenting decision making. - Involve stakeholders in preparedness planning.	- Consider the will of the individual. - Transparency to patients in decision making. - Second opinion useful for difficult cases. - Flexible/ eligible for local adaptation.
	Luxembourg	Netherlands	Poland	Portugal	Spain	Switzerland	UK
Source	Commission Nationale d'Éthique	Royal Dutch Medical Association	Polish Society of Anaesthesiology and Intensive Therapy	National Council of Ethics for the Life Sciences	Spanish Society of Intensive Critical Medicine and Coronary Units	Swiss Academy of Medical Sciences	National Institute of Health and Care Excellence; British Medical Association; Royal College of Physicians
Frailty	- Short/ medium-term prognosis, general health.	- Short-term prognosis with Clinical Frailty Score (including recovery time) but do not exclude ID/ physical disability based on daily support needs.	- Short-term prognosis. - Chronic, severe, end-of-life comorbid illness.	- None.	- Short-term prognosis. - Chronic, severe, end-of-life comorbid illness.	- Short-term prognosis and perceived benefit of intensive care. - Chronic, severe, end-of-life comorbid illness.	- Short-term prognosis with Clinical Frailty Score (comorbidities, benefit vs. risk, quality of life) but should not be used for younger people,

							those with stable/ chronic disabilities, autism/ ID.
Disability	- Discrimination based on disability absolutely prohibited.	- Creating capacity for care in neurodevelopmental/ residential care settings. - Should not consider 'mental/ physical limitation', nor prior quality of life.	- None.	- 'Special attention' to vulnerable groups. - Avoid inequalities in access to diagnostics/ treatments (e.g. for those with chronic conditions).	- Exclude 'severe baseline cognitive impairment'.	- Discrimination based on chronic disability precluded.	- Duty to not disadvantage one group disproportionately (e.g. disability). - Caution indirect discrimination e.g. 'first come first served'/ 'capacity to benefit quickly' may disadvantage those with disabilities.
Equity	- No exclusion based on non-medical criteria. - Value of each individual recognised as absolute. - All patients treated fairly and equally.	- Allocation criteria apply to all intensive care patients.	- None.	- Value of each individual recognised as absolute.	- Selection criteria must be equitably applied for all who would benefit from ICU.	- Equity crucial as recognised principle of medical ethics.	- Each individual matters equally; equal chance of benefitting from resources should mean equal chance of receiving them.
Other	- Consider the will of the individual. - Transparency to patients and in documenting decision making. - Involve local ethics advisory service.	- Transparency to patients and in documenting decision making. - 'The right care in the right place' (e.g. consider home treatment). - Triage informed by expert team.	- Focus on order of medical prioritisation, rather than inclusion/ exclusion criteria.	- Transparency to patients and the public in decision making. - Remove decision making responsibility from individual care providers. - Case-by-case decision making.	- Consider the will of the individual. - Transparency to patients and in documenting decision making. - Involve local ethics advisory service. - Exclude those who need resources	- Consider the will of the individual. - Transparency in documenting decision making. - Triage informed by expert team.	- Consider the will of the individual. - Transparency to patients and in documenting decision making. - Involve local ethics advisory service. - Flexibility in adaptable circumstances.

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that cannot be
provided.

Note: Malta is not included, since no publicly available triage recommendations/ documentation were identified.

Usual health and social care services for autistic people and those with ID 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 one year (a maximum of 13 weeks is recommended by the UK National Institute of Health and Care Excellence; 70,71). Considered ‘non-essential’ in light of the COVID-19 pandemic, cancelled/ postponed diagnostic appointments may further delay autistic people in accessing needs-based support (e.g. mental health interventions), which may be contingent on receiving a formal diagnosis.

Second, many community-based services across Europe (e.g. 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-19 (72) and are not always eligible to claim reimbursement for appointments that have been shifted to online delivery (though see flexible legislation from Belgium; 73), meaning some have been forced to close completely (74). As a result, for some autistic people/ those with ID, relatives and other caregivers are currently the only available support person. Of concern, 33.3% ($N=279$) of Autism-Europe survey respondents stated that their usual support person was at increased risk for COVID-19 and 62.5% ($N=523$) reported they did not have access to another support person if their usual caregiver became infected.

Last, with low capacity for testing and PPE provisions in residential care settings, 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 (38,75–77). These measures are designed to prevent infection spread in ‘high risk’ long-term care facilities. However, loss of contact with relatives/ caregivers (also constituting a change in routine) may cause distress for autistic people/ those with ID 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/ telephone contact (78). In addition, it is important that public health information is made accessible for the autism community – with 65.3% ($N=791$) of Autism-Europe survey respondents being unaware or unsure of accessible information about current COVID-19 measures.

Lastly, 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 (79). 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/ support or financial needs, and reducing the duty to prepare or review individual care/ support plans. We identified no published evidence to date that any local authorities in England have yet exercised social care easements (80). Nevertheless, it is essential that this continues to be closely monitored and proper data 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 (81,82).

Discussion

Summary of key findings and recommendations

We reviewed COVID-19 health and social care access for autistic people, including those with ID, across 15 European member states, based on published policies/ guidelines and results from a large-scale survey of over 1,300 autistic people and caregivers. Our findings highlighted several issues regarding COVID-19 service access for autistic people that require rapid consideration, in terms of accessibility of testing; treatment, hospitalisation and ICU care; and changes to standard health and social care provision.

Specifically, we identified: 1) failures to prioritise and/ or provide adequate adaptations to promote accessibility of testing, despite elevated risk of severe COVID-19 disease due to commonly co-occurring physical health problems; 2) barriers for accessing treatment (e.g. alternative communication needs) and ICU triage protocols that directly or indirectly (i.e. through their ambiguity) discriminate against those with additional needs; and 3) abrupt interruptions to existing service provision (e.g. mental health/ community-based services) without appropriate mitigation measures - further exacerbated by long-standing pressures on health and social care. Considering these issues, we formulated a set of four specific recommendations for improving health and social care access for autistic people/ those with ID in pandemic situations and other public health emergencies (Table 3).

Table 3.

Recommendations for an aligned European strategy for reducing inequalities in access to health and social care services for autistic people/ those with ID, in pandemic situations.

1. Autistic people and those with ID should be considered for priority access to proactive testing/ screening (even when apparently asymptomatic) in cases of insufficient testing capacity, if living in ‘high risk’ settings for disease transmission like residential care and supported accommodation.   To further promote equitable access to tests for all other individuals, accessibility of testing procedures can be enhanced by providing preparatory materials and considering flexible test procedures (e.g. saliva vs. swab testing).
2. If hospital admission is necessary, autistic people and those with ID 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 (where 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 (e.g. intensive care and autism communities), to inform an aligned European strategy on the fair allocation of resources in public health emergencies that does not inadvertently (nor explicitly) 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/ 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 (e.g. telehealth, needs- vs. diagnosis-based support).

Access to COVID-19 testing and screening

As outlined above, our first key finding was a failure to prioritise and/ or systematically provide adequate adaptations to promote access to testing for autistic people/ those with ID. COVID-19 strategies published by the World Health Organisation and European Commission emphasise the critical importance of testing suspected cases so that confirmed cases can be isolated and their close contacts traced (83,84). COVID-19 testing strategies and capacity have varied between European countries. However, broadly, infrastructure limitations (e.g. manual processing of test data, financial) and supply shortages

mean that testing capacity has fallen below growing demand across the EU (85). According to the World Health Organisation and European Commission, in the case of insufficient testing capacity, priority groups for rapid testing in EU countries should include those at elevated 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, like residential care homes (83,86). These criteria are highly relevant to autism, also given that high rates of difficulties identifying and describing symptoms (see reviews of interoception difficulties and alexithymia in autism 87,88) and/ or difficulties communicating with health providers represent a further challenge for recognise COVID-19 symptoms in autistic people.

Considering these issues, our first recommendation for an aligned European strategy for responding to pandemic situations is that – in the case of testing shortages - individuals with autism/ ID should be considered for priority access to testing if living in ‘high risk’ settings for disease transmission (even when apparently asymptomatic), like residential care and supported accommodation (Table 3).

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 like social stories and videos, available in different languages and easy-read formats, to demonstrate the testing procedure in advance (for

examples, please see 22,89). Moreover, for those who cannot tolerate swab testing, the use of non-invasive saliva sampling may be considered and can be readily performed at home. Of note, the utility of the saliva method for COVID-19 testing has been demonstrated (90,91) and is already approved by the US Food and Drug Administration and in use in some European regions, including Germany.

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 individuals and those with ID who require any treatment, hospitalisation or intensive care. This is significant, given that autistic people and those with ID often have suboptimal experiences of accessing healthcare and hospital admission (13–16) and experience higher odds for inpatient hospital mortality (92). Furthermore, the resources required to adequately support autistic individuals and those with ID during hospitalisation are likely to be considerably stretched in pandemic situations (68,93). Indeed, there have been concerns across Europe regarding the ‘surge’ capacity of healthcare systems to cope with acute increases in patients requiring hospital and intensive care beds (94).

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 (3,95). 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 (96,97). 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 (98–100).

Consequently, our second set of recommendations relate to proper resourcing and care planning, which must be implemented to support autistic people and those with ID who develop severe COVID-19 symptoms in general hospital settings (Table 3). These include:

- 1) Mandatory provision of accessible/ easy-read healthcare information and communication toolkits (for examples, please see 101,102);
- 2) Mandatory consultation with autistic people/ those with ID to provide prior information about themselves, their preferences and healthcare needs, in case they become unable to communicate on admission to hospital (e.g. the COVID-19 ‘Grab and Go’ Guide from 103). 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 (104);
- 3) Mandatory, regularly updated formal guidelines and training for all healthcare providers, co-developed with autistic people and those with ID and supported by access to specialist providers like learning disability/ psychiatric liaison staff (17,38,68);
- 4) Introducing flexibility to some regulations (where appropriate), such as allowing a caregiver or support person to accompany the individual into hospital, following all necessary infection control procedures (already in place in regions of Germany and the Netherlands, according to clinician reviews).

While these recommendations have been specifically applied to supporting the needs of autistic people and those with ID, it should be emphasised that they are likely more broadly beneficial for other groups. For instance, introducing flexibility to regulations may also support individuals with mental health conditions, like anxiety. Similarly, the provision of accessible healthcare information and communication toolkits would be equally applicable for individuals with sight/ hearing loss or speech and language difficulties (105).

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 (Table 3). Triage protocols must be reviewed prior to a second peak of COVID-19 in Europe. This is essential to prevent the widespread exclusion of autistic people and those with ID 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 may 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.

Access to existing health and social care services

Notably, with the proper resourcing and funding of health and social care systems, the prospective need to implement triage protocols is reduced. Following the economic crisis of 2008-2013, 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 (106). In addition, there is very little available evidence to suggest the most (cost-)effective ways to provide social care for autistic people (107).

Despite these issues, many non-emergency health and social care services have not altogether ceased as a result of COVID-19, but instead been shifted from in-person to remote/online delivery (i.e. ‘telehealth’). The fast implementation of telehealth in response to COVID-19 may have a positive impact on clinical practice in the longer-term (108,109), particularly for improving accessibility and reducing costs of health and social care services. For instance, one previous systematic review demonstrated that outcomes of telehealth assessment/ interventions for autistic people were broadly comparable to face-to-face consultations and superior to comparison groups who received no consultation at all (110). 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 (111). Thus, even prior to COVID-19, telehealth had been identified as a key area for promoting more effective, accessible and resilient European healthcare systems (112).

To ensure that telehealth fulfils its future positive potential to improve the quality of healthcare for autistic people and those with ID, it must be implemented in an accessible way (73,113). For instance, the European Disability Forum recommends that: all information is provided in plain, easy-read language; alternative methods are provided for those who communicate by different means or who do not have access to certain technologies (e.g. video, telephone, email/ messaging services); and the accessibility needs of different groups (including younger children) are considered – for example, appropriate sign language interpretation/ captioning and symbols (114). Some of these recommendations require that the care provider has specialist training on supporting autistic people and those with ID 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 is comprehensively reviewed to inform contingency plans for the safe and effective delivery

of services in the short- and longer-term (Table 3). This may include incorporating greater flexibility to ensure that services can quickly adapt to changing circumstances – for example, reducing the demand for a formal diagnosis of autism/ ID as a prerequisite for accessing needs-based support. Furthermore, there is a significant need for high quality and reliable data (81) to identify key areas for targeted restructuring and investment for improving health and social care provisions (e.g. strategies for earlier detection of support needs and early interventions) for autistic people and those with ID.

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/ those with ID. Many services and individual professionals have made considerable efforts to continue to support autistic people/ those with ID 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 (22,25,89). Additionally, some healthcare providers have implemented 24/7 telehealth services and live-in residential care (68). Several reasonable adjustments have also been made across Europe for autistic people and those with ID, including exceptions on wearing face masks in public and allowing increased daily exercise during lockdown periods. Lastly, in response to lobbying by non-profit organisations, new and amended guidance on supporting autistic people and those with ID 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 and those with ID in relation to COVID-19, which were beyond the scope of the current review, but must be investigated in future research. In particular, the mental and physical health impacts of COVID-19 should be assessed, given high reported rates of pandemic-related stressors amongst families with an autistic child (115) and possible long-term mental and physical health implications of COVID-19 infection (116,117). 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 and those with ID across 15 European countries, also capturing the lived experiences of over 1,300 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 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 (e.g. 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 was 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, since each have 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 (118,119). Similarly, the proportion of social care services provided by Government, non-profit and private organisations varies across Europe (119). To capture COVID-19 health and social care access, systematically adjusted for health system variability, it would be necessary to gather long-term (e.g. 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/ those with ID, prior to a second peak of the virus in Europe.

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 and those with ID. This is despite these groups being at elevated risk for severe illness and mortality, due to factors like frequently co-occurring physical health conditions, difficulties with symptom identification, and living in residential care settings. Barriers for accessing COVID-19 services included: 1) a lack of priority access to tests for those in 'high risk' residential settings and difficulties tolerating testing procedures; 2) inaccessibility of outpatient (e.g. telephone) and inpatient treatment, largely due to differences in communication needs; 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 four specific recommendations for an aligned European strategy to reduce health and

social care inequalities in public health emergencies, which require particularly urgent consideration in advance of a second peak of the virus in Europe.

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Author contributions

BO, JT and AR led on coordinating the project, analysis and writing the manuscript. AB and CT provided de-identified secondary data from the Autism-Europe survey. TC, EJ, JC, ES, JB and DM led on the study concept and development. MD, PV and LG provided additional study sources. All authors critically reviewed the manuscript and agreed on submission.

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Competing interests

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: JB reports personal fees from Servier, Angelini, Medice, F. Hoffmann-La Roche Ltd, Takeda/Shire, and Janssen / J&J. DM reports personal fees from Hoffmann-La Roche Ltd and reports grants from IMI2 - Joint Undertaking - No 777394, during the conduct of the study. JT reports personal fees from Hoffmann-La Roche Ltd. TC reports personal fees from F. Hoffmann-La Roche Ltd, Servier, Sage Publications, Guildford Publications, as well as grants from Medical Research Council, National Institute for Health Research, Horizon 2020, Innovative Medicines Initiative, Autistica, MQ, Charles Hawkins Fund, and The Waterloo Foundation, during the conduct of the study. For all authors above, the present work is unrelated to these relationships. All other authors have no competing interests to declare.