BMJ Open

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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-045341
Article Type:	Original research
Date Submitted by the Author:	29-Sep-2020
Complete List of Authors:	Oakley, Bethany; King's College London Tillmann, Julian; King's College London, Ruigrok, Amber; University of Cambridge Baranger, Aurélie; Autism Europe aisbl Takow, Christian; Autism Europe aisbl Charman, Tony; King's College London, Institute of Psychiatry, ; Jones, Emily; Birkbeck University of London Cusack, James; Autistica Doherty, Mary Violland, Pierre Wroczyńska, Agnieszka; Centrum Medyczne Grupa LUX MED Simonoff, Emily; King's College London, Institute of Psychiatry, Child & Adolescent Psychiatry Buitelaar, Jan; Radboud University Medical Centre, Donders Institute for Brain, Cognition and Behavior, Department of Cognitive Neuroscience, & Karakter Child and Adolescent Psychiatry University Centre Gallagher, Louise Murphy, Declan G. M.; King's College London
Keywords:	COVID-19, Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Child & adolescent psychiatry < PSYCHIATRY

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

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

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

[1]Department of Forensic and Neurodevelopmental Sciences, Institute of Psychiatry, Psychology & Neuroscience, King's College London, De Crespigny Park, SE5 8AF, UK

[2]Department of Psychology, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

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

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

[5]Autism-Europe, Rue Montoyer 39, Brussels 1000, Belgium

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

[7]Centre for Brain & Cognitive Development, Birkbeck, University of London, London, WC1E 7HX, UK

[8]Autistica, St Saviour's House, 39-41 Union Street, London, SE1 1SD

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

[10]Centrum Medyczne Grupa LUX MED – Gdańsk, al. Jana Pawła II 7

[11]Department of Child and Adolescent Psychiatry, Institute of Psychology, Psychiatry and Neuroscience, King's College London, London, UK

[12]Radboud University Nijmegen Medical Center, Donders Institute for Brain, Cognition and Behaviour, Department of Cognitive Neuroscience, Kapittelweg 29, 6525 EN Nijmegen, The Netherlands

[13]Karakter Child and Adolescent Psychiatry University Center, Reiner Postlaan 12, Nijmegen, The Netherlands

[14]Discipline of Psychiatry, Trinity Translational Medicine Institute, Trinity College Dublin,

[15]Sackler Institute for Translational Neurodevelopment, Institute of Psychiatry, Psychology & Neuroscience, King's College London, De Crespigny Park, SE5 8AF, UK

*Joint first authors

**Corresponding authors: julian.tillmann@kcl.ac.uk; bethany.oakley@kcl.ac.uk; 0207 848 0820; Forensic and Neurodevelopmental Sciences (PO 23), Institute of Psychiatry, Psychology & Neurosciences, King's College London, 16 de Crespigny Park, London SE5 8AF

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) access to COVID-19 tests; 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 accessibility 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 in many European countries (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.

Article summary

Strengths and limitations of this study

- The first comprehensive review of regional/ 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 1,300 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 and the rest of the world.
- 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/ survey data in some European countries.
- Self-selection of survey respondents and variation in the impact of COVID-19 across European countries may have introduced response and/ or publication biases that influenced the information available for this study.

Funding: This project was supported by the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 777394. This Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA and SFARI, Autistica, AUTISM SPEAKS.

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.

Introduction

Over 5 million SARS-CoV2 (hereafter COVID-19) cases and over 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 (including ID; 7,8). Furthermore, COVID-19 may disproportionately impact autistic people (at least 32% of whom have co-occurring ID; 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, 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; 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 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 (see also 11,12) and inconsistent specialist clinician training, awareness and knowledge about autism and ID (13,16,17). 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 (18).

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% (19,20). 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 (21) - 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 (22) and more detailed information has since been published by charities and clinical research teams (23–25), 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) access to COVID-19 testing/ 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 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 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 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.

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 - access to testing/ 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 (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 were 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.

Public and patient involvement

Representatives from the autism community were involved as active research partners in all aspects of the research by actively contributing to identify priority areas for policy review, review policy guidelines in selected countries and interpreting findings/making recommendations for policy guidance. Autism-Europe, a European non-profit organisation for autistic people and their families, independently designed the survey content and questions and collected all responses. Representatives from the autism community and Autism-Europe contributed to editing the manuscript and are coauthors. Dissemination of the current results will be achieved through the AIMS-2-TRIALS consortium, through the large family network of Autism-Europe and conference presentations. Policy makers at the national and European level will be encouraged to review COVID-19 guidelines in light of the results.

Results

Access to COVID-19 testing and screening

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, auto-immune conditions, diabetes, obesity and hypertension (10–12). 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%; 27).

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; 29,30).

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 UK and Republic of Ireland, care home residents (including asymptomatic cases) were not officially added to the list for priority access to COVID testing until 29th and 17th April 2020, respectively – at least two months after the first confirmed COVID-19 cases in these regions (28,34). 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 (26,27).

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 in case of shortages 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 2**Error! Reference source not found.**). 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 hrs 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 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, 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 83,84). 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 premorbid 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 that	- 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.

					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; NHS Digital, 2019). Considered 'non-essential' in light of the COVID-19 pandemic, cancelled/ postponed diagnostic appointments may further delay those with autism/ ID 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 (71) and are not always eligible to claim reimbursement for appointments that have been shifted to online delivery (though see flexible legislation from Belgium; 91), meaning some have been forced to close completely (73). 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 (38,74–76). 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 (77). 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 (78). 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 (79). 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 (80,81).

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/ those with ID that require rapid consideration, in terms of testing/ 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/ or 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/ hospitalisation (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 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/ 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 (8,82). 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 (83). 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 (8,84). 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 by DuBois, Ameis, Lai, Casanova, & Desarkar, 2016; Kinnaird, Stewart, & Tchanturia, 2019) 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

18,38). 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 (86,87) 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 (13,16,17,88) and experience higher odds for inpatient hospital mortality . Furthermore, the resources required to adequately support autistic individuals and those with ID during hospitalisation are likely to be considerably stretched in pandemic situations (68,89). 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 (90).

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 (3,91). 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 (92,93). 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 (94–96).

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 52,53);

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 54). 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 (100);

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 (38,68,101);

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 (102).

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 potential 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 (103). In addition, there is very little available evidence to suggest the most (cost-)effective ways to provide social care for autistic people (104).

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 (105,106), 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 (107). 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 (108). Thus, even prior to COVID-19, telehealth had been identified as a key area for promoting more effective, accessible and resilient European healthcare systems (109).

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 (110,111). 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 (also see 107). 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 (80) 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 (25,85,113). 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 (114), and possible long-term mental and physical health implications of COVID-19 infection (115,116). 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 (117,118). Similarly, the proportion of social care services provided by Government, non-profit and private organisations varies across Europe (118). To capture COVID-19 health and social care access, systematically adjusted for health system variability, it would be necessary to gather long-term data (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 potential future peak of the virus.

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 testing and difficulties tolerating swab 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 potential future peak of the virus or future pandemic.

References

1. World Health Organization. Coronavirus disease (COVID-19) Weekly Epidemiological Update 21st September 2020 [Internet]. 2020. Available from: https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200921-weekly-epi-update-6.pdf?sfvrsn=d9cf9496_6

2. Bayer R, Bernheim RG, Crawley LM, Daniels N, Goodman K, Kass N, et al. Ethical Considerations for Decision Making Regarding Allocation of Mechanical Ventilators during a Severe Influenza Pandemic or Other Public Health Emergency [Internet]. 2011. Available from: https://www.cdc.gov/about/advisory/pdf/VentDocument_Release.pdf

3. Emanuel EJ, Persad G, Upshur R, Thome B, Parker M, Glickman A, et al. Fair Allocation of Scarce Medical Resources in the Time of Covid-19. N Engl J Med [Internet]. 2020 Mar 23; Available from: https://doi.org/10.1056/NEJMsb2005114

4. Hale T, Angrist N, Kira B, Petherick A, Phillips T, Webster S. Variation in government responses to COVID-19. 2020.

5. European Centre for Disease Prevention and Control. Coronavirus disease 2019 (COVID-19) in the EU/ EEA and the UK – eighth update 8 April 2020 [Internet]. Vol. 2019. 2020. Available from: https://www.ecdc.europa.eu/sites/default/files/documents/covid-19-rapid-risk-assessment-coronavirus-disease-2019-eighth-update-8-april-2020.pdf

6. Pellicano E, Stears M. The hidden inequalities of COVID-19. Autism [Internet]. 2020 May 18;1362361320927590. Available from: https://doi.org/10.1177/1362361320927590

7. Centre for Public Representation. COVID-19 Medical Rationing & Hospital Visitor Policies [Internet]. 2020. Available from: https://www.centerforpublicrep.org/covid-19-medical-rationing/

8. World Health Organization. COVID-19 Strategy Update 4th April 2020 [Internet]. 2020. Available from: https://www.who.int/docs/default-source/coronaviruse/covid-strategy-update-14april2020.pdf?sfvrsn=29da3ba0_19

9. MacKay T, Boyle J, Connolly M, Knapp M, Iemmi V, Rehill A. The Microsegmentation of the Autism Spectrum: Economic and Research Implications for Scotland [Internet]. Edinburgh: The Scottish Government; 2018. Available from: https://strathprints.strath.ac.uk/67058/1/MacKay_etal_SG2018_The_microsegmentation_of_the_autism_spectrum.pdf

10. Croen LA, Zerbo O, Qian Y, Massolo ML, Rich S, Sidney S, et al. The health status of adults on the autism spectrum. Autism Int J Res Pract. 2015 Oct;19(7):814–23.

11. Flygare Wallén E, Ljunggren G, Carlsson AC, Pettersson D, Wändell P. High

prevalence of diabetes mellitus, hypertension and obesity among persons with a recorded diagnosis of intellectual disability or autism spectrum disorder. J Intellect Disabil Res. 2018 Apr;62(4):269–80.

12. Jordan RE, Adab P, Cheng KK. Covid-19: risk factors for severe disease and death. BMJ [Internet]. 2020;368. Available from: https://www.bmj.com/content/368/bmj.m1198

13. Doherty M, Sullivan JD, Neilson SD. Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study. medRxiv [Internet]. 2020; Available from: https://www.medrxiv.org/content/early/2020/04/06/2020.04.01.20050336

14. DuBois D, Ameis S, Lai M-C, Casanova M, Desarkar P. Interoception in Autism Spectrum Disorder: A Review. Int J Dev Neurosci. 2016 Jun 1;52.

15. Kinnaird E, Stewart C, Tchanturia K. Investigating alexithymia in autism: A systematic review and meta-analysis. Eur psychiatry J Assoc Eur Psychiatr. 2019 Jan;55:80–9.

16. Mason D, Ingham B, Urbanowicz A, Michael C, Birtles H, Woodbury-Smith M, et al. A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. J Autism Dev Disord [Internet]. 2019;49(8):3387–400. Available from: https://doi.org/10.1007/s10803-019-04049-2

17. Nicolaidis C, Raymaker DM, Ashkenazy E, McDonald KE, Dern S, Baggs AE, et al. "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. Autism Int J Res Pract [Internet]. 2015/04/16. 2015 Oct;19(7):824–31. Available from: https://pubmed.ncbi.nlm.nih.gov/25882392

18. NHS England. Supporting patients of all ages who are unwell with coronavirus (COVID-19) in mental health, learning disability, autism, dementia and specialist inpatient facilities [Internet]. 2020. Report No.: 30 April. Available from: https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0290_Supporting-patients-who-are-unwell-with-COVID-19-in-MHLDA-settings.pdf

19. Care Quality Commission. CQC publishes data on deaths of people with a learning disability [Internet]. 02 June. 2020. Available from: https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability

20. Office for National Statistics. Deaths registered weekly in England and Wales, provisional [Internet]. 09 June. 2020. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/weeklyprovisionalfiguresondeathsregisteredinenglandandwales

21. World Health Organisation Regional Office for Europe. Strengthening the health system response to COVID-19: Preventing and managing the COVID-19 pandemic

across long-term care services in the WHO European Region (21 May 2020) [Internet]. 2020. Available from: https://apps.who.int/iris/bitstream/handle/10665/333067/WHO-EURO-2020-804-40539-54460-eng.pdf?sequence=1&isAllowed=y

22. World Health Organisation. Disability considerations during the COVID-19 outbreak [Internet]. 2020. (20 March). Available from: https://www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1

23. Alexander RT. People with Intellectual Disability and Mental Health/Behavioural Problems: Guidance on COVID-19 for Inpatient Settings [Internet]. Norwich: RADiANT.; 2020. Available from: http://radiant.nhs.uk/uploads/2/7/2/5/27254761/alexander__2020__guidance_on_covid-19_for_inpatient_id_settings.pdf

24. Inclusion Europe. Coronavirus (COVID-19) pandemic [Internet]. 2020. Available from: https://www.inclusion-europe.eu/coronavirus-pandemic/

25. Autism Europe. The autism community mobilizes itself to face COVID-19 [Internet]. 20 March. 2020 [cited 2020 Jun 30]. Available from: https://www.autismeurope.org/blog/2020/03/20/the-autism-community-mobilizes-itself-to-face-covid-19/

26. National Institute for Public Health and the Environment. Policy on testing for novel coronavirus disease (COVID-19) [Internet]. 2020. Available from: https://www.rivm.nl/en/node/154261

27. Sciensano. Hospital procedure for approaching a patient with possible/ confirmed COVID-19 [Internet]. 2020. Available from: https://covid-19.sciensano.be/sites/default/files/Covid19/COVID-19_procedure_hospitals_NL.pdf

28. UK Department of Health and Social Care. Coronavirus (COVID-19): getting tested [Internet]. 2020. Available from: https://www.gov.uk/guidance/coronavirus-covid-19-getting-tested

29. Clark A, Jit M, Warren-Gash C, Guthrie B, Wang HHX, Mercer SW, et al. Global, regional, and national estimates of the population at increased risk of severe COVID-19 due to underlying health conditions in 2020: a modelling study. Lancet Glob Heal [Internet]. 2020 Aug 1;8(8):e1003–17. Available from: https://doi.org/10.1016/S2214-109X(20)30264-3

30. Buescher AVS, Cidav Z, Knapp M, Mandell DS. Costs of autism spectrum disorders in the United Kingdom and the United States. JAMA Pediatr [Internet]. 2014;168(8):721–8. Available from: https://www.scopus.com/inward/record.uri?eid=2-s2.0-84905180333&doi=10.1001%2Fjamapediatrics.2014.210&partnerID=40&md5=b3b7ee0eb6dcdcdc769d3bcf77bc90d7

31. Shinn AK, Viron M. Perspectives on the COVID-19 Pandemic and Individuals With

Serious Mental Illness. J Clin Psychiatry. 2020 Apr;81(3).

32. World Health Organisation. Rational use of personal protective equipment for coronavirus disease 2019 (COVID-19) [Internet]. 2020. Available from: https://apps.who.int/iris/bitstream/handle/10665/331215/WHO-2019-nCov-IPCPPE_use-2020.1-eng.pdf

33. Organisation for Economic Development and Cooperation. OECD Policy Responses to Coronavirus (COVID-19) - Testing for COVID-19: A way to lift confinement restrictions [Internet]. 2020. Report No.: 4 May. Available from: https://www.oecd.org/coronavirus/policy-responses/testing-for-covid-19-a-way-to-lift-confinement-restrictions-89756248/#endnotea0z16

34. Health Protection Surveillance Centre. Interim Public Health, Infection Prevention & Control Guidelines on the Prevention and Management of COVID-19 Cases and Outbreaks in Residential Care Facilities [Internet]. 2020. Available from: https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/guidance/outbreakmanagementguidance/RCF guidance document.pdf

35. Tomchek SD, Dunn W. Sensory Processing in Children With and Without Autism : A Comparative Study Using the Short Sensory Profile. Am J Occup Ther. 2007;61(2).

36. Uljarević M, Baranek G, Vivanti G, Hedley D, Hudry K, Lane A. Heterogeneity of sensory features in autism spectrum disorder: Challenges and perspectives for future research. Autism Res. 2017 May;10(5):703–10.

37. European Centre for Disease Prevention and Control. Diagnostic testing and screening for SARS-CoV-2 [Internet]. 2020. Available from: https://www.ecdc.europa.eu/en/covid-19/latest-evidence/diagnostic-testing

38. Istituto Superiore di Sanità. Interim Indications for appropriate support of people on the autistic spectrum in the current emergency scenario SARS-CoV-2 [Internet]. 2020. Report No.: 30 March. Available from: vhttps://www.iss.it/documents/20126/0/Rapporto+ISS+COVID-19+n.+8+autismo+%282%29.pdf/c558b34e-1bc9-c868-0c75-0030f8299bca?t=1585757457709

39. Agency for Care and Health. Covid-19 - Mental health care [Internet]. 2020. Available from: https://www.zorg-en-gezondheid.be/corona-richtlijnen-voor-zorgprofessionals

40. European Disability Forum. Open letter to leaders at the EU and in EU countries: COVID-19 - disability inclusive response [Internet]. 13 March. 2020. Available from: http://edf-feph.org/newsroom/news/open-letter-leaders-eu-and-eu-countries-covid-19-disability-inclusive-response

41. NHS Providers. The impact of COVID-19 on mental health trusts in the NHS [Internet]. 2020. Available from: https://nhsproviders.org/media/689590/spotlight-on-mental-health.pdf

42. Council of Europe. Bioethics COVID-19: Selected resources by country [Internet]. 2020. Available from: https://www.coe.int/en/web/bioethics/selected-resources-by-country/

43. Federation of Medical Specialists. Guidance: Triage home treatment versus referral to hospital in elderly patients with (suspected) COVID-19 [Internet]. 2020. (7 May). Report No.: 3. Available from: https://translate.google.com/translate?hl=en&sl=nl&u=https://www.demedischspecialist.nl/sites/default/files/Leidraad%2520triage%2520thuisbehandeling%2520versus%2520verwijzen%2520oudere%2520pati%25C3%25ABnt%2520met%2520verdenking%2520COVID-19.pdf&prev=search&pto=aue

44. Joebges S, Biller-Andorno N. Ethics guidelines on COVID-19 triage—an emerging international consensus. Crit Care [Internet]. 2020;24(1):201. Available from: https://doi.org/10.1186/s13054-020-02927-1

45. Ethics Working Group of the Austrian Society for Anaesthesiology Resuscitation and Intensive Care. Allocation of intensive care medical resources: Occasion of the Covid 19 pandemic [Internet]. 2020. Available from: https://www.oegari.at/web_files/cms_daten/covid-19_ressourcenallokation_gari-statement_v1.7_final_2020-03-17.pdf

46. Austria Bioethics Commission. Management of scarce resources in healthcare in the context of the COVID-19 pandemic: Opinion of the Bioethics Commission [Internet]. 2020. Available from: https://rm.coe.int/management-scarce-resources/16809e40f1

47. Azoulay É, Beloucif S, Guidet B, Pateron D, Vivien B, Le Dorze M. Admission decisions to intensive care units in the context of the major COVID-19 outbreak: local guidance from the COVID-19 Paris-region area. Crit Care [Internet]. 2020;24(1):293. Available from: https://doi.org/10.1186/s13054-020-03021-2

48. German Interdisciplinary Association for Intensive Care and Emergency Medicine. Decisions on the allocation of intensive care medicine resources in the context of the COVID-19 pandemic (Version 2) [Internet]. 2020. Available from: https://www.awmf.org/uploads/tx_szleitlinien/040-013l_S1_Zuteilung-intensivmedizinscher-Ressourcen-COVID-19-Pandemie-Klinisch-ethische_Empfehlungen_2020-04.pdf

49. Department of Health Ireland. Ethical Framework for Decision-Making in a Pandemic [Internet]. 2020. Available from: https://www.gov.ie/en/publication/dbf3fb-ethical-framework-for-decision-making-in-a-pandemic/

50. Italian Society of Anaesthesia Analgesia Resuscitation and Intensive Care. Clinical Ethics Recommendations for the Allocation of Intensive Care Treatments in exceptional, resource-limited circumstances - Version n. 1 Posted on March, 16. 2020;1–8.

51. Clarfield AM, Dwolatzky T, Brill S, Press Y, Glick S, Shvartzman P, et al. Israel Ad

Hoc COVID-19 Committee: Guidelines for Care of Older Persons During a Pandemic. J Am Geriatr Soc [Internet]. 2020;11 May. Available from: https://doi.org/10.1111/jgs.16554

52. Cassidy SA, Nicolaidis C, Davies B, Rosa SDR, Eisenman D, Onaiwu MG, et al. An Expert Discussion on Autism in the COVID-19 Pandemic. Autism in Adulthood [Internet]. 2020 May 8;2(2):106–17. Available from: https://doi.org/10.1089/aut.2020.29013.sjc

53. Health Service Journal. Learning disabilities patients told they may be 'too frail' for mechanical ventilation if they get covid-19 [Internet]. 4 April. 2020. Available from: https://www.hsj.co.uk/coronavirus/learning-disabilities-patients-told-they-may-be-too-frail-for-mechanical-ventilation-if-they-get-covid-19/7027318.article

54. Hong J, Bishop-Fitzpatrick L, Smith LE, Greenberg JS, Mailick MR. Factors Associated with Subjective Quality of Life of Adults with Autism Spectrum Disorder: Self-Report Versus Maternal Reports. J Autism Dev Disord. 2016 Apr;46(4):1368–78.

55. Tavernor L, Barron E, Rodgers J, Mcconachie H. Finding out what matters: Validity of quality of life measurement in young people with ASD. Child Care Health Dev. 2013;39(4):592–601.

56. Moss P, Mandy W, Howlin P. Child and Adult Factors Related to Quality of Life in Adults with Autism. J Autism Dev Disord [Internet]. 2017 Jun;47(6):1830–7. Available from: https://pubmed.ncbi.nlm.nih.gov/28343343

57. Hodge and Allen Solicitors. NICE amends COVID-19 critical care guidelines after judicial review challenge [Internet]. Vol. 31 March. 2020. Available from: https://www.hja.net/press-releases/nice-amends-covid-19-critical-care-guideline-after-judicial-review-challenge/

58. Mencap. Mencap responds to new NICE COVID-19 guidance [Internet]. 02 April. 2020. Available from: https://www.mencap.org.uk/press-release/mencap-responds-deeply-troubling-new-nice-covid-19-guidance

59. National Institute of Health and Care Excellence. COVID-19 rapid guideline: critical care in adults [Internet]. 2020. Report No.: 20 March. Available from: https://www.nice.org.uk/guidance/ng159/resources/covid19-rapid-guideline-critical-care-in-adults-pdf-66141848681413

60. Montgomery J, Stokes-Lampard HJ, Griffiths MD, Gardiner D, Harvey D, Suntharalingam G. Assessing whether COVID-19 patients will benefit from critical care, and an objective approach to capacity challenges during a pandemic: An Intensive Care Society clinical guideline. J Intensive Care Soc [Internet]. 2020 Aug 17;1751143720948537. Available from: https://doi.org/10.1177/1751143720948537

61. NVAVG. Guidance referral of the adult patient with an intellectual disability and (suspected) COVID-19 [Internet]. 2020. Report No.: 15 April. Available from: https://translate.googleusercontent.com/translate_c?depth=1&hl=en&prev=search&pto

=aue&rurl=translate.google.com&sl=nl&sp=nmt4&u=https://nvavg.nl/wp-content/uploads/2020/04/NVAVG_Covid-19_leidraad.pdf&usg=ALkJrhjFUhRYRyvgthG2T1ECCGY-7qvnaA

62. Royal Dutch Medical Association. Scenario Triage based on non-medical considerations for IC inclusion at the time of phase 3 in the COVID-19 pandemic [Internet]. 2020. Available from: https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/publicaties/2020/06/16/draaiboek-triage-op-basis-van-niet-medische-overwegingen-voor-ic-opname-ten-tijde-van-fase-3-in-de-covid-19-pandemie/draaiboek-triage-op-basis-van-niet-medische-overwegingen-voor-ic-opname-ten-tijde-van-fase-3-in-de-covid-19-pandemie.pdf

63. The Spanish Society of Intensive Critical Medicine and Coronary Units. Plan de contingencia para loc servicios de medicina intensiva frente a la pandemia COVID-19 [Internet]. 2020. Available from: https://www.semicyuc.org/covid19_files/Plan_de_Contingencia_COVID-19.pdf

64. Devereaux A V, Dichter JR, Christian MD, Dubler NN, Sandrock CE, Hick JL, et al. Definitive Care for the Critically Ill During a Disaster: A Framework for Allocation of Scarce Resources in Mass Critical Care: From a Task Force for Mass Critical Care Summit Meeting, January 26–27, 2007, Chicago, IL. Chest [Internet]. 2008 May 1;133(5):51S–66S. Available from: https://doi.org/10.1378/chest.07-2693

65. Biddison LD, Berkowitz KA, Courtney B, De Jong CMJ, Devereaux A V, Kissoon N, et al. Ethical Considerations: Care of the Critically Ill and Injured During Pandemics and Disasters: CHEST Consensus Statement. Chest [Internet]. 2014 Oct 1;146(4):e145S–e155S. Available from: https://doi.org/10.1378/chest.14-0742

66. Spanish Bioethics Committee. Report of the Spanish Bioethics Committee on bioethics aspects of the prioritisation of sanitary resources in the context of the coronavirus crisis [Internet]. 2020. Available from: http://assets.comitedebioetica.es/files/documentacion/Informe CBE- Priorizacion de recursos sanitarios-coronavirus CBE.pdf

67. Spanish Ministry of Health. Ministry of Health report on ethical issues in pandemic situations: SARS-CoV-2 [Internet]. 2020. Report No.: 3 April. Available from: https://rm.coe.int/pandemic-covid-19-spain-eng/16809e3a78

68. Arango C. Lessons Learned From the Coronavirus Health Crisis in Madrid, Spain: How COVID-19 Has Changed Our Lives in the Last 2 Weeks. Biol Psychiatry [Internet]. 2020 Apr 8;S0006-3223(20)31493-1. Available from: https://pubmed.ncbi.nlm.nih.gov/32381276

69. Autism Spain. Autism Spain prepares a document of de-escalation proposals for entities and services specialized in people with autism and their families [Internet]. 2020. Available from: http://www.autismo.org.es/actualidad/articulo/autismo-espana-elabora-un-documento-de-propuestas-de-desescalada-para-entidades

70. NHS Digital. Autism Statistics [Internet]. 2019. Available from: https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics/autism-statistics

71. European Association of Service providers for Persons with Disabilities. The impact of COVID-19 on disability services in Europe [Internet]. 2020. Available from: https://www.easpd.eu/sites/default/files/sites/default/files/Publications2020/impact_of_covid-19_on_disability_services_in_europe_a_first_snapshot.pdf

72. National Institute for Health and Disability Insurance. Medical care and benefits insurance: exceptional measures to combat COVID 19 [Internet]. 2020. Available from: https://www.riziv.fgov.be/nl/covid19/Paginas/default.aspx

73. Social Care Institute for Excellence. Understanding the impact of COVID-19 responses on citizens [Internet]. 2020. Available from: https://www.scie.org.uk/care-providers/coronavirus-covid-19/commissioning/impact-on-citizens

74. Cautreels M, Heiremans M. Corona pushes disabled care into the corner where the blows fall [Internet]. 2020. Available from: https://sociaal.net/opinie/corona-duwt-gehandicaptenzorg-in-hoek-waar-de-klappen-vallen/

75. Ministry of Health Wellbeing and Sports. New visitors scheme for care for the disabled and mental health care [Internet]. 2020. Available from: https://www.rijksoverheid.nl/onderwerpen/coronavirus-covid-19/nieuws/2020/03/23/nieuwe-bezoekersregeling-gehandicaptenzorg-en-ggz

76. European Centre for Disease Prevention and Control. Surveillance of COVID-19 at longterm care facilities in the EU/EEA [Internet]. 2020. Available from: https://www.ecdc.europa.eu/sites/default/files/documents/covid-19-long-term-care-facilities-surveillance-guidance.pdf

77. UK Department of Health and Social Care. Update on policies for visiting arrangements in care homes [Internet]. 2020. Report No.: 31 July. Available from: https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus/update-on-policies-for-visiting-arrangements-in-care-homes

78. UK Department of Health and Social Care. Care Act easements: guidance for local authorities [Internet]. 2020. Available from: https://www.gov.uk/government/publications/coronavirus-covid-19-changes-to-the-care-act-2014/care-act-easements-guidance-for-local-authorities#purpose-of-the-easements

79. Care Quality Commission. The Care Act and the ‘easements’ to it [Internet]. 2020. Available from: https://www.cqc.org.uk/guidance-providers/adult-social-care/care-act-easements-it

80. Hodgson K, Grimm F, Vestesson E, Brine R, Deeny S. Briefing: Adult social care and COVID-19 Assessing the impact on social care users and staff in England so far [Internet]. 2020. Report No.: July. Available from:

https://www.health.org.uk/publications/reports/adult-social-care-and-covid-19-assessing-the-impact-on-social-care-users-and-staff-in-england-so-far

81. Amon J, Wurth M. A Virtual Roundtable on COVID-19 and Human Rights with Human Rights Watch Researchers. Heal Hum Rights J. 2020;22(1):399–414.

82. European Commission. Testing kits for COVID-19: What is the EU doing? [Internet]. 2020. Available from: https://ec.europa.eu/health/sites/health/files/preparedness_response/docs/testingkits_factsheet.pdf

83. European Centre for Disease Prevention and Control. An overview of the rapid test situation for COVID-19 diagnosis in the EU / EEA [Internet]. 2020. Available from: https://www.ecdc.europa.eu/sites/default/files/documents/Overview-rapid-test-situation-for-COVID-19-diagnosis-EU-EEA.pdf

84. European Commission. COVID-19 EU recommendations for testing strategies. 2020.

85. AsIAm. AsIAm and COVID-19. 2020.

86. Williams E, Bond K, Zhang B, Putland M, Williamson DA. Saliva as a non-invasive specimen for detection of SARS-CoV-2. J Clin Microbiol. 2020;50(April).

87. To KK-W, Tsang OT-Y, Leung W-S, Tam AR, Wu T-C, Lung DC, et al. Temporal profiles of viral load in posterior oropharyngeal saliva samples and serum antibody responses during infection by SARS-CoV-2: an observational cohort study. Lancet Infect Dis [Internet]. 2020 May 1;20(5):565–74. Available from: https://doi.org/10.1016/S1473-3099(20)30196-1

88. Nicolaidis C, Raymaker D, McDonald K, Dern S, Boisclair WC, Ashkenazy E, et al. Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership. J Gen Intern Med [Internet]. 2012/11/21. 2013 Jun;28(6):761–9. Available from: https://pubmed.ncbi.nlm.nih.gov/23179969

89. Pratt K, Baird G, Gringras P. Ensuring successful admission to hospital for young people with learning difficulties, autism and challenging behaviour: A continuous quality improvement and change management programme. Child Care Health Dev [Internet]. 2012;38(6):789–97. Available from: https://www.scopus.com/inward/record.uri?eid=2-s2.0-84867401412&doi=10.1111%2Fj.1365-2214.2011.01335.x&partnerID=40&md5=ad8a224830506d6d895daea3bda9a4c7

90. World Health Organisation. Strengthening the health system response to COVID-19 in the WHO transmission scenarios: Action points for the WHO European Region [Internet]. 2020. Report No.: 01 April. Available from: https://www.euro.who.int/__data/assets/pdf_file/0005/436352/strengthening-health-system-response-COVID-19-WHO-transmission-scenarios.pdf

91. World Health Organisation. Strengthening the health system response to COVID-19: Recommendations for the WHO European Region [Internet]. 2020. Report No.: 01 April. Available from: https://www.euro.who.int/__data/assets/pdf_file/0003/436350/strengthening-health-system-response-COVID-19.pdf

92. Truog RD, Mitchell C, Daley GQ. The Toughest Triage — Allocating Ventilators in a Pandemic. N Engl J Med [Internet]. 2020 Mar 23;382(21):1973–5. Available from: https://doi.org/10.1056/NEJMp2005689

93. New York State Task Force on Life and the Law & New York State Department of Health. Ventilator Allocation Guidelines [Internet]. 2015. Report No.: November. Available from: https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf

94. European Court of Human Rights. European Convention on Human Rights [Internet]. Strasbourg; 2010. Available from: https://www.echr.coe.int/Documents/Convention_ENG.pdf

95. United Nations. Convention on the rights of persons with disabilities. 2008.

96. International Disability Alliance. An Open Letter to the World Health Organisation [Internet]. 2020. Available from: http://www.internationaldisabilityalliance.org/sites/default/files/ida_letter_to_who_march_31_2020.pdf

97. Mencap. Coronavirus: Information about going to hospital [Internet]. 2020. Available from: https://www.mencap.org.uk/advice-and-support/coronavirus-covid-19/coronavirus-information-about-going-hospital

98. Widgit. Critical Care Covid-19 Communication Chart [Internet]. 2020. Available from: https://www.widgit.com/products/health/covid19-communication-chart.htm

99. NHS England. COVID-19 Grab and Go Guide - Form [Internet]. 2020. Available from: https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0381-nhs-covid-19-grab-and-go-lda-form.pdf

100. House of Lords Hansard. Covid-19: Social Care Services [Internet]. Vol. 803. 2020. Available from: https://hansard.parliament.uk/Lords/2020-04-23/debates/0D93005E-2D8C-4994-98A0-AABD6341841A/Covid-19SocialCareServices?highlight=covid#contribution-872EF5DC-BE3B-4042-9C19-723E54CB19E8

101. NHS England. Clinical guide for front line staff to support the management of patients with a learning disability, autism or both during the coronavirus pandemic – relevant to all clinical specialities [Internet]. 2020. Report No.: 24 March Version 1. Available from: https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0031_Specialty-guide_LD-and-coronavirus-v1_-

24-March.pdf

102. Grote H, Izagaren F. Covid-19: The communication needs of D/deaf healthcare workers and patients are being forgotten. BMJ. 2020 Jun;369:m2372.

103. Thomson S, Figueras J, Evetovits T, Jowett M, Mladovsky P, Maresso A, et al. Economic crisis, health systems and health in Europe: impact and implications for policy [Internet]. 2014. Available from: https://www.euro.who.int/__data/assets/pdf_file/0008/257579/Economic-crisis-health-systems-Europe-impact-implications-policy.pdf?ua=1

104. Smith E, Kenny L, Harper G, Bradshaw J, Chesterman E, Shorthouse J, et al. Action Briefing: Social Care. 2020.

105. Galletly C. Psychiatry in the COVID-19 Era. Aust New Zeal J Psychiatry [Internet]. 2020 May 1;54(5):447–8. Available from: https://doi.org/10.1177/0004867420920359

106. Vieta E, Pérez V, Arango C. Psychiatry in the aftermath of COVID-19. Rev Psiquiatr y Salud Ment [Internet]. 2020; Available from: http://www.sciencedirect.com/science/article/pii/S188898912030029X

107. Sutherland R, Trembath D, Roberts J. Telehealth and autism: A systematic search and review of the literature. Int J Speech Lang Pathol. 2018 Jun;20(3):324–36.

108. Little LM, Wallisch A, Pope E, Dunn W. Acceptability and Cost Comparison of a Telehealth Intervention for Families of Children With Autism. Infants Young Child [Internet]. 2018;31(4). Available from: https://journals.lww.com/iycjournal/Fulltext/2018/10000/Acceptability_and_Cost_Comparison_of_a_Telehealth.3.aspx

109. European Commission. Strategic Plan 2016-2020: DG Health and Food Safety [Internet]. 2017. Available from: https://ec.europa.eu/info/sites/info/files/strategic-plan-2016-2020-dg-sante_en_0.pdf

110. Office of the Federal Council for the Mental Health Professions. Mental Health Care provided remotely by GGZ-professionals in the context of the Covid-19quarantine measures [Internet]. 2020. Available from: https://overlegorganen.gezondheid.belgie.be/sites/default/files/documents/20200401-bureaufrggzb-nota_nl_covid-19.pdf

111. Ameis SH, Lai M-C, Mulsant BH, Szatmari P. Coping, fostering resilience, and driving care innovation for autistic people and their families during the COVID-19 pandemic and beyond. Mol Autism [Internet]. 2020;11(1):61. Available from: https://doi.org/10.1186/s13229-020-00365-y

112. Noel K, Ellison B. Inclusive innovation in telehealth. npj Digit Med [Internet]. 2020;3(1):89. Available from: https://doi.org/10.1038/s41746-020-0296-5

113. Autistica. Coronavirus and autism [Internet]. 2020. Available from: https://www.autistica.org.uk/what-is-autism/coronavirus

114. Pearcey S, Shum A, Waite P, Creswell C. Supplementary Report 03: Differences in pandemic anxiety, parent/carer stressors and reported needs between parent/carers of children with and without ASD; Change over time in mental health for children with ASD. [Internet]. 2020. Available from: https://emergingminds.org.uk/wp-content/uploads/2020/07/Co-SPACE-supplementary-report-03-final.pdf

115. Asadi-Pooya AA, Simani L. Central nervous system manifestations of COVID-19: A systematic review. J Neurol Sci. 2020 Jun;413:116832.

116. D'Agostino A, Demartini B, Cavallotti S, Gambini O. Mental health services in Italy during the COVID-19 outbreak. The Lancet Psychiatry [Internet]. 2020 May 1;7(5):385–7. Available from: https://doi.org/10.1016/S2215-0366(20)30133-4

117. European Parliament. Health Care Systems in the EU: A Comparative Study [Internet]. 1998. Available from: https://www.europarl.europa.eu/workingpapers/saco/pdf/101_en.pdf

118. Robertson R, Gregory S, Jabbal J. The social care and health systems of nine countries [Internet]. 2014. Available from: https://www.kingsfund.org.uk/sites/default/files/media/commission-background-paper-social-care-health-system-other-countries.pdf

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.

Acknowledgements

We would like to thank the AIMS-2-TRIALS Clinical Trials Network and Early Career Researchers in Autism Network for their contributions and support for this project. We particularly acknowledge: Roderik Plas, Agnieszka Wroczynska, Katrien van den Bosch, Evdokia Anagnostou, Sofie Boterberg, Herbert Roeyers, Guillame Dumas, Frédérique Bonnet-Brilhault, Louise Poutska, Christine Freitag, Filippo Muratori, Eugenia Conti, Erik Mulder, Giorgia Bussu, Anne Smit, Elke de Jonge, Manon Krol, Ciara Molloy, Julia Koziel, Célia Rasga, Sonija Luzi, Monica Burdeus, Laura Gisbert, Antonia San José Cáceres, Eleni Kroupi, Covadonga Martinez, Alvaro Beja, Miriam Rivero Contreras, María Manzano Arjona, Clara Janisel Fernández Álvarez, Ruth Campos, Alicia Alcon, Jorge Lugo, Imanol Setien, Gara Arteaga, Ana Blazquez and Dominika Zofia Wojcik.

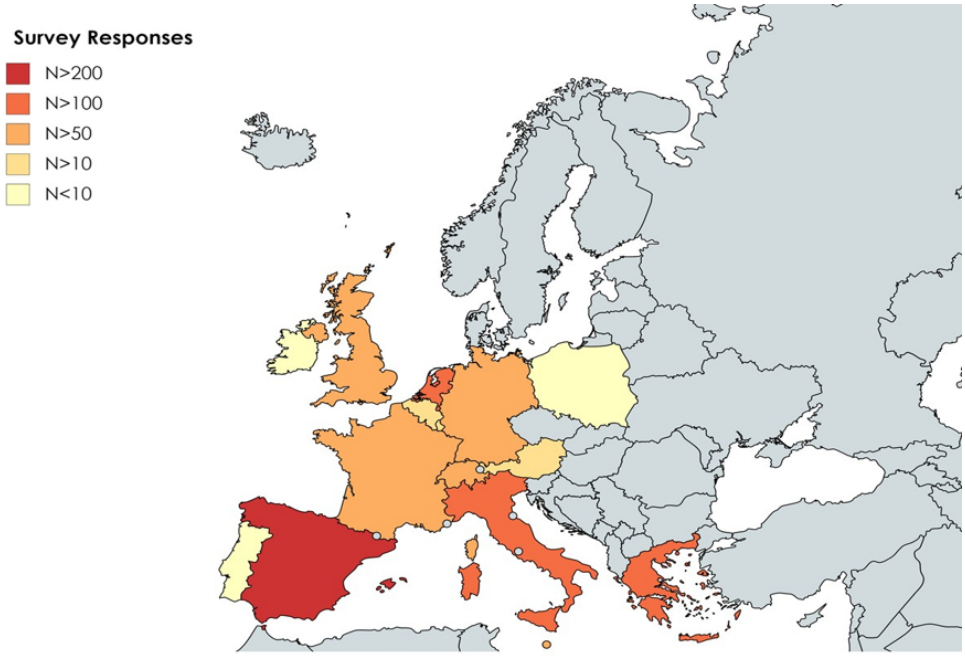


Figure 1. Schematic highlighting the 15 European countries included in this study, colour coded by number of Autism-Europe survey responses from each region: Spain *N*=304; Italy *N*=192; Greece *N*=165; Netherlands *N*=143; Switzerland *N*=144; France *N*=86; United Kingdom *N*=66; Germany *N*=60; Malta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

Supplementary Table 1

Autism-Europe survey respondents, by country.

Region	Respondent	*N*	Age categories of autistic person			
			0-18	18-40	41-65	65+
Austria	Autistic person	5	0	4	1	0
	Relative	7	5	1	1	0
Belgium	Autistic person	19	1	9	9	0
	Relative	15	3	4	8	0
France	Autistic person	31	0	21	9	1
	Relative	55	13	12	26	4
Germany	Autistic person	39	1	25	12	1
	Relative	21	3	8	9	1
Greece	Autistic person	6	1	4	1	0
	Relative	159	6	46	107	0
Ireland	Autistic person	3	0	2	1	0
	Relative	2	1	0	1	0
Italy	Autistic person	14	4	4	6	0
	Relative	178	12	30	122	14
Luxembourg	Autistic person	14	0	11	3	0
	Relative	19	3	1	12	3
Malta	Autistic person	1	0	1	0	0
	Relative	52	11	24	16	1
Netherlands	Autistic person	99	7	45	46	1
	Relative	44	4	10	30	0
Poland	Autistic person	1	0	1	0	0
	Relative	2	0	1	0	1
Portugal	Autistic person	0	0	0	0	0
	Relative	1	0	0	0	1
Spain	Autistic person	13	1	10	2	0
	Relative	291	27	61	192	11
Switzerland	Autistic person	57	3	34	19	1
	Relative	87	16	17	53	1
United Kingdom	Autistic person	44	2	18	23	1
	Relative	22	1	6	13	2

Supplementary Material 1

Common review templates for COVID-19 health and social care policies/ guidelines, distributed to the: a) AIMS-2-TRIALS early career autism researchers and panel of representatives from the autism community and; b) AIMS-2-TRIALS Clinical Trials Network.

a)

Enter: Country/ Region					
Source	**Summary of evidence**				
Full source reference (include date and weblink, where relevant)	**Access to COVID-19 screening/ testing**	**Hospitalisation/ intensive care**	**Social care/ self-isolation**	**Changes to usual healthcare practice**	**Other comments/ issues** **OR** **Review**
Include publication date and, where relevant, the full weblink.	Consider: test availability; test procedure (e.g. sensory); getting test results; any other issues.	Consider: availability of hospital/ intensive care beds; triage/ resource allocation; inclusion/ exclusion criteria; provision and quality of care; resuscitation orders; discharge procedures; any other issues.	Consider: provision of social/ residential/ community care; support for individuals who are self-isolating or shielding; any other issues.	Consider: access to/ delivery of standard services (e.g. mental health, remote delivery).	Any other comments, notes, guidelines, policies. OR Professional commentary on changes to regional services/ official guidance on service access (for AIMS-2-TRIALS Clinical Trials Network).

Supplementary Table 2.

List of published policies/ guidelines included in this study, with source of access documented.

Publication	Date	Language	Source of access
Belgium			
National Public Health Institute (Sciensano)	20/05/2020	Dutch	https://covid-19.sciensano.be/sites/default/files/Covid19/COVID-19_procedure_hospitals_NL.pdf
Ethics committee for care in UZ Leuven	17/03/2020	Dutch	https://cdn.digisecure.be/grip/2020331121514529_leidraad-voor-ethisch-handelen-uz-leuven.pdf
Belgian Society of Intensive Care Medicine	18/03/2020	English	https://www.hartcentrumhasselt.be/professioneel/nieuws-professioneel/ethical-principles-concerning-proportionality-of-critical-care-during-the-covid-19-pandemic-advice-by-the-belgian-society-of-ic-medicine%20
Federal Public Service Social Security	29/05/2020	Dutch	https://www.socialsecurity.be/citizen/nl/static/infos/coronavirus/index.htm# https://www.socialsecurity.be/citizen/nl/static/infos/coronavirus/index.htm#
Agency for Care and Health	18/03/2020	Dutch	https://www.zorg-en-gezondheid.be/sites/default/files/atoms/files/maatregelen%20COVID_19_GGZ_200318.pdf
FPS Public Health, Food Chain Safety and Environment of Belgium	01/04/2020	Dutch	https://overlegorganen.gezondheid.belgie.be/sites/default/files/documents/20200401-bureaufrggzb-nota_nl_covid-19.pdf
Department of Welfare, Public Health and Family	13/04/2020	Dutch	https://www.departementwvg.be/sites/default/files/media/20200414_Taskforce_wob.pdf
Belgium Society of Emergency and Disaster Medicine and the Belgian Resuscitation Council	22/03/2020	English	https://www.ordeartsenbrabant.org/assets/images/BESEDIM_26mars2020_Ethical-decision-making-in-emergencies_COVID19_22032020_final.pdf
Flemish Agency for Persons with a Disability	21/04/2020	Dutch	https://www.vaph.be/sites/default/files/documents/15117/infonota_20_102_compenserende_maatregelen_nav_covid-19_7_.pdf
Flemish Agency for Persons with a Disability	15/04/2020	Dutch	https://www.vaph.be/nieuws/de-impact-van-de-coronacrisis-op-personen-met-een-verstandelijke-handicap-enof
National Employment Office	01/07/2020	Dutch/German/French	https://www.rva.be/nl/documentatie/infoblad/t9-0#h2_0
Agency for Care and Health	17/03/2020	Dutch	https://www.zorg-en-gezondheid.be/sites/default/files/atoms/files/Maatregelen_corona_RCA_17_03_20.pdf
Fédération Wallonie-Bruxelles	17/03/2020	French	http://www.enseignement.be/index.php?page=28294
National Institute for Health and Disability Insurance	N/A	Dutch	https://www.riziv.fgov.be/nl/covid19/Paginas/default.aspx

The Netherlands			
Ministry of Health, Wellbeing and Sports	23/03/2020	Dutch	https://www.rijksoverheid.nl/onderwerpen/coronavirus-covid-19/zorg/geestelijke-gezondheidszorg-ggz https://www.rijksoverheid.nl/onderwerpen/coronavirus-covid-19/nieuws/2020/03/23/nieuwe-bezoekersregeling-gehandicaptenzorg-en-ggz
National Institute for Public Health and the Environment	17/08/2020	Dutch	https://lci.rivm.nl/covid-19/PBMbuitenziekenhuis
Dutch Youth Institute	19/08/2020	Dutch	https://www.nji.nl/nl/coronavirus/Professionals/Fysiek-contact-bij-ambulante-hulpverlening-bij-het-coronavirus
Federation of Medical Specialists		Dutch	https://www.demedischspecialist.nl/sites/default/files/Leidraad%20triage%20thuisbehandeling%20versus%20verwijzen%20oudere%20pati%C3%ABnt%20met%20verdenking%20COVID-19.pdf
Association of Mental Health Physicians	14/04/2020	Dutch	https://nvavg.nl/wp-content/uploads/2020/04/NVAVG_Covid-19_leidraad.pdf
Royal Dutch Medical Association	16/06/2020	Dutch	https://www.rijksoverheid.nl/documenten/publicaties/2020/06/16/draaiboek-triage-op-basis-van-niet-medische-overwegingen-voor-ic-opname-ten-tijde-van-fase-3-in-de-covid-19-pandemie
United Kingdom			
UK Department of Health and Social Care	12/08/2020	English	https://www.gov.uk/guidance/coronavirus-covid-19-getting-tested
NHS England		English	https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0290_Supporting-patients-who-are-unwell-with-COVID-19-in-MHLDA-settings.pdf
NHS Providers	03/06/2020	English	https://nhsproviders.org/media/689590/spotlight-on-mental-health.pdf
Health Protection Surveillance Centre	28/07/2020	English	https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/guidance/outbreakmanagementguidance/RCF guidance document.pdf
Social Care Institute for Excellence	29/06/2020	English	https://www.scie.org.uk/care-providers/coronavirus-covid-19/commissioning/impact-on-citizens
National Institute of Health and Care Excellence	20/03/2020	English	https://www.nice.org.uk/guidance/ng159/resources/covid19-rapid-guideline-critical-care-in-adults-pdf-66141848681413
UK Department of Health and Social Care	31/07/2020	English	https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus/update-on-policies-for-visiting-arrangements-in-care-homes https://www.gov.uk/government/publications/coronavirus-covid-19-changes-to-the-care-act-2014/care-act-easements-guidance-for-local-authorities#purpose-of-the-easements
Care Quality Commission	03/07/2020	English	https://www.cqc.org.uk/guidance-providers/adult-social-care/care-act-easements-it
Italy			
Osservatorio Nazionale Autismo ISS, Istituto Superiore di Sanità	30/03/2020	Italian	https://www.iss.it/documents/20126/0/Rapporto+ISS+COVID-19+n.+8+autismo+%282%29.pdf/c558b34e-1bc9-c868-0c75-0030f8299bca?t=1585757457709
Italian Society of Anaesthesia Analgesia Resuscitation and Intensive Care			http://www.siaarti.it/SiteAssets/News/COVID19%20-%20documenti%20SIAARTI/SIAARTI%20-%20Covid-19%20-%20Clinical%20Ethics%20Reccomendations.pdf
Ethics Working Group of the	17/03/2020	German	https://www.oegari.at/web_files/cms_daten/covid-19_ressourcenallokation_gari-statement_v1.7_final_2020-03-17.pdf

Austrian Society for Anaesthesiology Resuscitation and Intensive Care			
Austria Bioethics Commission	31/03/2020	German	https://rm.coe.int/management-scarce-resources/16809e40f1
German Interdisciplinary Association for Intensive Care and Emergency Medicine	17/04/2020	German	https://www.awmf.org/uploads/tx_szleitlinien/040-013l_S1_Zuteilung-intensivmedizinscher-Ressourcen-COVID-19-Pandemie-Klinisch-ethische_Empfehlungen_2020-07_2.pdf
Ireleand			
Department of Health Ireland	27/03/2020	English	https://www.gov.ie/en/publication/dbf3fb-ethical-framework-for-decision-making-in-a-pandemic/
European guidelines			
Council of Europe	N/A	Various languages	https://www.coe.int/en/web/bioethics/selected-resources-by-country/
European Centre for Disease Prevention and Control	19/05/2020	English	https://www.ecdc.europa.eu/sites/default/files/documents/covid-19-long-term-care-facilities-surveillance-guidance.pdf
European Association of Service providers for Persons with Disabilities	04/2020	English	https://www.easpd.eu/sites/default/files/sites/default/files/Publications2020/impact_of_covid-19_on_disability_services_in_europe_a_first_snapshot.pdf
World Health Organisation	23/04/2020	English	https://www.euro.who.int/en/health-topics/health-emergencies/coronavirus-covid-19/statements/statement-invest-in-the-overlooked-and-unsung-build-sustainable-people-centred-long-term-care-in-the-wake-of-covid-19
Spain			
The Spanish Society of Intensive Critical Medicine and Coronary Units.	14/03/2020	Spanish	https://www.semicyuc.org/covid19_files/Plan_de_Contingencia_COVID-19.pdf
Spanish Bioethics Committee	23/03/2020	Spanish	http://assets.comitedebioetica.es/files/documentacion/Informe%20CBE-%20Priorizacion%20de%20recursos%20sanitarios-coronavirus%20CBE.pdf
Spanish Ministry of Health	03/04/2020	English	https://rm.coe.int/pandemic-covid-19-spain-eng/16809e3a78
Autism Spain	05/05/2020	Spanish	http://www.autismo.org.es/actualidad/articulo/autismo-espana-elabora-un-documento-de-propuestas-de-desescalada-para-entidades
France			
Ministry of Disability	04/05/2020	French	https://handicap.gouv.fr/IMG/pdf/04052020_-_les_grandes_lignes_du_plan_de_deconfinement_pour_les_personnes_en_situation_de_handicap_vd.pdf https://handicap.gouv.fr/autisme-et-troubles-du-neuro-developpement/infos-speciales-coronavirus/article/information-covid-19-et-confinement
President of the Republic	02/04/2020 17/03/2020	French	https://www.elysee.fr/emmanuel-macron/2020/04/02/autisme https://www.gouvernement.fr/sites/default/files/contenu/piece-jointe/2020/03/ attestation-deplacement-falc.pdf

Poland			
Organisation for the Help of Autistic People	06/04/2020	Polish	https://www.gdansk.pl/wiadomosci/sytuacja-osob-z-autyzmem-w-dobie-koronawirusa-rozmowa-z-malgorzata-rybicka,a,168209
National Fund for the Rehabilitation of Disabled People (PFRON)	02/03/2020	Polish	https://www.pfron.org.pl/aktualnosci/szczegoly-aktualnosci/news/pomoc-pfron-dla-osob-niepelnosprawnych-w-zwiazku-z-epidemia-koronawirusa/
Portugal			
The Portuguese Ministry of Health	18/04/2020	Portuguese	https://www.dgs.pt/directrizes-da-dgs/normas-e-circulares-normativas/norma-n-0112020-de-18042020-pdf.aspx

Supplementary Table 3

Autism-Europe survey items included in this review.

Autism-Europe survey items
Are you considered to be within the group at higher risk for COVID-19?
Were you tested for COVID-19? *If yes:* Did you receive adequate/ accessible information about getting tested for COVID-19? *If yes:* Were any reasonable adjustments provided for autism needs during testing for COVID-19?
Did you have to get treated in relation to COVID-19? *If yes:* Did you experience difficulty to contact healthcare professionals/ first aid responders during the COVID-19 spread? *If yes:* Was it due to the inaccessibility of the process e.g. contact to be made by phone?
Do you need support for daily activities? Have your usual support services been interrupted since the beginning of the COVID-19 spread?
Are your support person(s) considered at higher risk for COVID-19? If your support person(s) get(s) infected, do you have another support person?
Is there accessible information available for autistic people on the COVID-19 spread and the current measures in place where you live?
If you would like to make any comment, use the field below – optional.

BMJ Open

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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-045341.R1
Article Type:	Original research
Date Submitted by the Author:	28-Jan-2021
Complete List of Authors:	Oakley, Bethany; King's College London Tillmann, Julian; King's College London, Ruigrok, Amber; University of Cambridge Baranger, Aurélie; Autism Europe aisbl Takow, Christian; Autism Europe aisbl Charman, Tony; King's College London, Institute of Psychiatry, ; Jones, Emily; Birkbeck University of London Cusack, James; Autistica Doherty, Mary; Our Lady's Hospital, Department of Anaesthesia Violland, Pierre; Autism Europe aisbl Wroczyńska, Agnieszka; Centrum Medyczne Grupa LUX MED Simonoff, Emily; King's College London, Institute of Psychiatry, Child & Adolescent Psychiatry Buitelaar, Jan; Radboud University Medical Centre, Donders Institute for Brain, Cognition and Behavior, Department of Cognitive Neuroscience, & Karakter Child and Adolescent Psychiatry University Centre Gallagher, Louise ; Trinity College, Discipline of Psychiatry, Trinity Translational Medicine Institute Murphy, Declan G. M.; King's College London
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Health policy, Public health
Keywords:	COVID-19, Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Child & adolescent psychiatry < PSYCHIATRY

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

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

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

[1]Department of Forensic and Neurodevelopmental Sciences, Institute of Psychiatry, Psychology & Neuroscience, King's College London, De Crespigny Park, SE5 8AF, UK

[2]Department of Psychology, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

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

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

[5]Autism-Europe, Rue Montoyer 39, Brussels 1000, Belgium

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

[7]Centre for Brain & Cognitive Development, Birkbeck, University of London, London, WC1E 7HX, UK

[8]Autistica, St Saviour's House, 39-41 Union Street, London, SE1 1SD

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

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

[11]Department of Child and Adolescent Psychiatry, Institute of Psychology, Psychiatry and Neuroscience, King's College London, London, UK

[12]Radboud University Nijmegen Medical Center, Donders Institute for Brain, Cognition and Behaviour, Department of Cognitive Neuroscience, Kapittelweg 29, 6525 EN Nijmegen, The Netherlands

[13]Karakter Child and Adolescent Psychiatry University Center, Reiner Postlaan 12, Nijmegen, The Netherlands

[14]Discipline of Psychiatry, Trinity Translational Medicine Institute, Trinity College Dublin,

[15]Sackler Institute for Translational Neurodevelopment, Institute of Psychiatry, Psychology & Neuroscience, King's College London, De Crespigny Park, SE5 8AF, UK

*Joint first authors

**Corresponding authors: julian.tillmann@kcl.ac.uk; bethany.oakley@kcl.ac.uk; 0207 848 0820; Forensic and Neurodevelopmental Sciences (PO 23), Institute of Psychiatry, Psychology & Neurosciences, King's College London, 16 de Crespigny Park, London SE5 8AF

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 March-July 2020, pertaining to: 1) access to COVID-19 tests; 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 experienced significant barriers accessing COVID-19 services. First, despite being at elevated risk for 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. Last, 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, likely contributing to disproportionate increases in morbidity and mortality, mental health/ behavioural difficulties and reduced quality of life. Policies and guidelines regarding the accessibility of COVID-19 services require urgent update to prevent the widespread exclusion of autistic people from services, which represents a violation of international human rights law.

Article summary

Strengths and limitations of this study

- The first comprehensive review of regional/ 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 1,301 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/ survey data in some European countries.
- Self-selection of survey respondents and variation in the impact of COVID-19 across European countries may have introduced response and/ or publication biases that influenced the information available for this study.

Funding: This project was supported by the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 777394. This Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA and SFARI, Autistica, AUTISM SPEAKS. The views expressed are those of the author(s) and not necessarily those of the IMI 2JU.

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. JT reports personal fees from Hoffmann-La Roche Ltd. TC reports personal fees from F.

Hoffmann-La Roche Ltd, Servier, Sage Publications, Guildford Publications. For all authors above, the present work is unrelated to these relationships. All other authors have no competing interests to declare.

Introduction

Over 26 million SARS-CoV2 (hereafter COVID-19) cases and 550,000 coronavirus-related deaths had been confirmed in Europe by the close of 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, may be particularly vulnerable to being excluded from services, support and treatment in pandemic situations (6).

Reports from the US 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, 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; 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/ interpretation difficulties, which can lead to misunderstandings by healthcare providers and reduced involvement of patients in healthcare decision making (and may 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 (e.g. around physical examinations, mask wearing); difficulties identifying and/ or describing pains and symptoms; and inconsistent specialist clinician training, awareness and knowledge about autism and ID (13–15). Health providers may also misattribute COVID-19 symptoms to existing medical, mental health or behavioural problems, including autism itself ('diagnostic overshadowing'), increasing risk for 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 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% (17,18). 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 (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 Organisation in March 2020 (20) 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.

Hence, we collated and reviewed regional/ national policies and guidelines from 15 European member states, covering three priority areas: 1) access to COVID-19 testing/ 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 for) 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 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 about here --

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 - access to testing/ 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 (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 were not clearly defined), and those who opened but did not answer survey

questions. This resulted in a final convenience sample of 1,301, including 346 autistic people and 955 caregivers. Please see Supplementary Table 1 for survey demographics.

Survey items requested from Autism-Europe for the purpose of this review are documented in Supplementary Table 3. The survey was disseminated publicly online between April 7th and May 31st 2020, in ten 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/ co-authoring the manuscript. Autism-Europe independently designed the survey content and collated all responses.

Results

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

Accessibility of COVID-19 testing/ 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, 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 of autistic people experience physical health comorbidities that are associated with elevated risk of developing severe disease on contracting COVID-19, including cardiovascular/ respiratory illness, auto-immune conditions, diabetes, obesity and hypertension.

Second, approximately 5-25% of autistic people live in residential care (i.e. higher intensity nursing/ large group homes) and up to a further 27% in supported accommodation (i.e. lower intensity congregate care settings in the community), with upper bound estimates referring to those with co-occurring intellectual disability (27). 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; 28,29).

Despite existing evidence for increased risk of poor outcomes from COVID-19, our review indicated that autistic people 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 (30). In the UK and Republic of Ireland, care home residents (including asymptomatic cases) were not officially added to the list for priority access to COVID testing until 29th and 17th April 2020, respectively – at least two months after the first confirmed COVID-19 cases in these regions (26,31). 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 (24,25), with the Netherlands being the only region to directly specify individuals with serious behavioural problems in residential care for priority testing.

However, we did not identify any additional published guidance, nor strategies specifically for enhancing accessibility of testing for autistic people across any other region reviewed in this study. For instance, even in the regions 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. This included a lack of guidance on 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/ 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/ hospitalisation

Next, we reviewed current recommendations for the admission of autistic people 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 existing designated specialist neurodevelopmental/ 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 (e.g. 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 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 (38).

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 1).

For example, several European countries with published triage protocols recommend the consideration of 'functional status' and/ or use of 'frailty assessments' – including the UK, Ireland, France, Netherlands, Italy, Belgium, Austria and Germany (39–47). These assessments were originally designed with reference to elderly populations, to indicate 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 between autistic people but may also be broadly underestimated due to a reliance on 'neurotypical' indicators of wellbeing (51).

In light of these concerns - and in response to challenges by advocacy groups and a proposed judicial review (52,53) - 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 intellectual disability (54,55). They also added weblinks to ethical guidance from medical associations (9th April 2020) and stated that – where they are appropriate - 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 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 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 (58). 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*" (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 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 61,62) - yet, they may be informing clinical decision-making (63).

Table 1.

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	Department of Health	Italian Society of Anaesthesia, Analgesia, Resuscitation and Intensive Care
Date of publication	31st March 2020; 17th March 2020	22nd March 2020; 17th March 2020	5th June 2020; 13th March 2020	17th April 2020	August 2017[a]	27th March 2020	16th March 2020
'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 premorbid 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	- 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.

			impact those with disabilities.				
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
Date of publication	31st March 2020	16th June 2020	October 2012[a]	3rd April 2020	21st March 2020	24th March 2020	29th April 2020; April 2020; 2nd April 2020
Frailty	- Short/ medium-term prognosis, general health.	- Short-term prognosis with Clinical Frailty Score (including recovery time) **but** do	- Short-term prognosis.	- None.	- Short-term prognosis.	- Short-term prognosis and perceived benefit of intensive care.	- Short-term prognosis with Clinical Frailty Score

		not exclude ID/ physical disability based on daily support needs.	- Chronic, severe, end-of-life comorbid illness.		- Chronic, severe, end-of-life comorbid illness.	- Chronic, severe, end-of-life comorbid illness.	(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.	- Transparency to patients and in documenting decision making. - 'The right care in the right place' (e.g. consider home treatment).	- Focus on order of medical prioritisation, rather than inclusion/ exclusion criteria.	- Transparency to patients and the public in decision making. - Remove decision making responsibility	- Consider the will of the individual. - Transparency to patients and in documenting decision making.	- 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.	- Triage informed by expert team.		from individual care providers. - Case-by-case decision making.	- Involve local ethics advisory service. - Exclude those who need resources that cannot be provided.		- Involve local ethics advisory service. - Flexibility in adaptable circumstances.

Note: ID=Intellectual disability. Malta is not included, since no publicly available triage recommendations/ documentation were identified.
[a]Current COVID-19 specific triage protocols were not identified, however existing information was available regarding allocation of resources in the case of shortages.

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 one year (a maximum of 13 weeks is recommended by the UK National Institute of Health and Care Excellence; 65). 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 (66) 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 person.

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/ caregivers (also constituting a change in routine) may 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/ telephone contact (72) – though it should be acknowledged that these options are not sufficient or appropriate for all individuals.

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 (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/ 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 (74). Nevertheless, it is essential that this 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/ screening

Corresponding to findings from our policy review - detailed above – results from Autism-Europe's survey of autistic people and caregivers (please see Table 2) also indicated that despite being considered at increased risk from 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 1). Furthermore, only 39% (*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 hrs 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.

Indeed, 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; 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."

Moreover, concerns regarding inequalities in access to COVID-19 services may 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 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

Last, 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 for COVID-19 and 63% (*N*=523) reported they did not have access to another support person if their usual caregiver became infected.

Table 2.

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

	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	6 (86%)	1 (14%)	0 (0%)
Require daily/ 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%)

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/ 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 testing/ 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/ or 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/ hospitalisation (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 recommendations for policy and clinical practice to improve health and social care access for autistic people 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.

Policy recommendations

1. Policy documentation should explicitly outline strategies for promoting equitable access to testing/ 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 (e.g. 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/ 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 (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 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/ 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) and community-based care.
Clinical practice recommendations
1. Mandatory provision of alternative, accessible/ easy-read healthcare information and communication toolkits (for examples, please see 76,77).
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 (e.g. the COVID-19 'Grab and Go' Guide; 78). 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 (79).
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/ psychiatric liaison staff (35,63,80).
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 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.

Enhancing accessibility of COVID-19 testing/ 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. 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 (81,82). 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 (83). 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, such as residential care homes (81,84) – criteria highly relevant to a proportion of autistic people.

However, it must be acknowledged that many autistic people experience additional barriers that may 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; 85,86), which may lead to late, missed or misdiagnosis and difficulties gaining access to appropriate treatments.

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 individuals

should be considered for priority access to testing if living in 'high risk' settings for disease transmission (even when apparently asymptomatic), such as 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 87). 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 (88,89) and is already approved by the US Food and Drug Administration, and in use in some European regions, 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 individuals 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 for inpatient hospital mortality. Furthermore, the resources required to adequately support autistic individuals during hospitalisation are

likely to be considerably stretched in pandemic situations (90). Indeed, there have been (and are currently) concerns across Europe regarding the 'surge' capacity of healthcare systems to cope with acute increases in patients requiring hospital and intensive care beds (91).

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 (92,93). 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 (94–96) and reflected in the ICU triage protocols of 8 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 (Table 3).

While these recommendations have been specifically applied to supporting the needs of autistic people, 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 intellectual disability (but not autism), other neurodevelopmental conditions (e.g. ADHD and behavioural problems) and 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 (97).

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). This 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 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.

Enhancing 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 (98). In addition, there is very little available evidence to suggest the most (cost-)effective ways to provide social care for autistic people (99).

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 (100,101), 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 (102). 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 (103). Thus, even prior to COVID-19, telehealth had been identified as a key area for promoting more effective, accessible and resilient European healthcare systems (104).

However, there is a lack of research regarding the most effective and appropriate methods for implementing telehealth services that ensure continuity of care, nor 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 ID, more research is required on how it can be implemented in an accessible and personalised way (105,106). 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 (107). 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 for autistic people 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 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 data (75) 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.

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 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 (23,87,108). 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. Lastly, 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, including: the impact of isolation; changes in education/ 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 amongst families with an autistic child (109–111), and possible long-term mental and physical health implications of COVID-19 infection (112,113). 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 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, combined with lived experiences from the autism community through survey data, 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 (114,115). Similarly, the proportion of social care services provided by Government, non-profit and private organisations varies across Europe (115). To capture COVID-19 health and social care access, systematically adjusted for health system variability, it would be necessary to gather long-term data (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, 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 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, 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 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. Barriers for accessing COVID-19 services included: 1) a lack of accessibility of testing, including difficulties tolerating swab procedures; 2) inaccessibility of outpatient and inpatient treatment, largely due to differences in communication needs (e.g. 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 four specific recommendations for an aligned European strategy to reduce health and social care inequalities in public health emergencies, which require particularly urgent consideration to enhance the future care of autistic people both during and beyond the pandemic.

References

1. World Health Organization. Coronavirus disease (COVID-19) Situation Report [Internet]. 2020. Available from: https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200614-covid-19-sitrep-146.pdf?sfvrsn=5b89bdad_4
2. Bayer R, Bernheim RG, Crawley LM, Daniels N, Goodman K, Kass N, et al. Ethical Considerations for Decision Making Regarding Allocation of Mechanical Ventilators during a Severe Influenza Pandemic or Other Public Health Emergency [Internet]. 2011. Available from: https://www.cdc.gov/about/advisory/pdf/VentDocument_Release.pdf
3. Emanuel EJ, Persad G, Upshur R, Thome B, Parker M, Glickman A, et al. Fair Allocation of Scarce Medical Resources in the Time of Covid-19. N Engl J Med [Internet]. 2020 Mar 23; Available from: https://doi.org/10.1056/NEJMsb2005114
4. Hale T, Angrist N, Kira B, Petherick A, Phillips T, Webster S. Variation in government responses to COVID-19. 2020.
5. European Centre for Disease Prevention and Control. Coronavirus disease 2019 (COVID-19) in the EU/ EEA and the UK – eighth update 8 April 2020 [Internet]. Vol. 2019. 2020. Available from: https://www.ecdc.europa.eu/sites/default/files/documents/covid-19-rapid-risk-

assessment-coronavirus-disease-2019-eighth-update-8-april-2020.pdf

6. Pellicano E, Stears M. The hidden inequalities of COVID-19. Autism [Internet]. 2020 May 18;1362361320927590. Available from: https://doi.org/10.1177/1362361320927590

7. The Center for Public Integrity. State policies may send people with disabilities to the back of the line for ventilators [Internet]. 2020. Available from: https://publicintegrity.org/health/coronavirus-and-inequality/state-policies-may-send-people-with-disabilities-to-the-back-of-the-line-for-ventilators/

8. MacKay T, Boyle J, Connolly M, Knapp M, Iemmi V, Rehill A. The Microsegmentation of the Autism Spectrum: Economic and Research Implications for Scotland [Internet]. Edinburgh: The Scottish Government; 2018. Available from: https://strathprints.strath.ac.uk/67058/1/MacKay_etal_SG2018_The_microsegmentation_of_the_autism_spectrum.pdf

9. Charman T, Jones CRG, Pickles A, Simonoff E, Baird G, Happé F. Defining the cognitive phenotype of autism. Brain Res. 2011;1380(1943):10–21.

10. Croen LA, Zerbo O, Qian Y, Massolo ML, Rich S, Sidney S, et al. The health status of adults on the autism spectrum. Autism Int J Res Pract. 2015 Oct;19(7):814–23.

11. Flygare Wallén E, Ljunggren G, Carlsson AC, Pettersson D, Wändell P. High prevalence of diabetes mellitus, hypertension and obesity among persons with a recorded diagnosis of intellectual disability or autism spectrum disorder. J Intellect Disabil Res. 2018 Apr;62(4):269–80.

12. Jordan RE, Adab P, Cheng KK. Covid-19: risk factors for severe disease and death. BMJ [Internet]. 2020;368. Available from: https://www.bmj.com/content/368/bmj.m1198

13. Doherty M, Sullivan JD, Neilson SD. Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study. medRxiv [Internet]. 2020; Available from: https://www.medrxiv.org/content/early/2020/04/06/2020.04.01.20050336

14. Mason D, Ingham B, Urbanowicz A, Michael C, Birtles H, Woodbury-Smith M, et al. A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. J Autism Dev Disord [Internet]. 2019;49(8):3387–400. Available from: https://doi.org/10.1007/s10803-019-04049-2

15. Nicolaidis C, Raymaker DM, Ashkenazy E, McDonald KE, Dern S, Baggs AE, et al. "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. Autism Int J Res Pract [Internet]. 2015/04/16. 2015 Oct;19(7):824–31. Available from: https://pubmed.ncbi.nlm.nih.gov/25882392

16. NHS England. Supporting patients of all ages who are unwell with coronavirus (COVID-19) in mental health, learning disability, autism, dementia and specialist inpatient facilities [Internet]. 2020. Report No.: 30 April. Available from: https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0290_Supporting-patients-who-are-unwell-with-COVID-19-in-MHLDA-settings.pdf

17. Care Quality Commission. CQC publishes data on deaths of people with a learning

disability [Internet]. 02 June. 2020. Available from: https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability

18. Office for National Statistics. Deaths registered weekly in England and Wales, provisional [Internet]. 09 June. 2020. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/weeklyprovisionalfiguresondeathsregisteredinenglandandwales

19. World Health Organisation Regional Office for Europe. Strengthening the health system response to COVID-19: Preventing and managing the COVID-19 pandemic across long-term care services in the WHO European Region (21 May 2020) [Internet]. 2020. Available from: https://apps.who.int/iris/bitstream/handle/10665/333067/WHO-EURO-2020-804-40539-54460-eng.pdf?sequence=1&isAllowed=y

20. World Health Organisation. Disability considerations during the COVID-19 outbreak [Internet]. 2020. (20 March). Available from: https://www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1

21. Alexander RT. People with Intellectual Disability and Mental Health/Behavioural Problems: Guidance on COVID-19 for Inpatient Settings [Internet]. Norwich: RADiANT.; 2020. Available from: http://radiant.nhs.uk/uploads/2/7/2/5/27254761/alexander__2020__guidance_on_covid-19_for_inpatient_id_settings.pdf

22. Inclusion Europe. Coronavirus (COVID-19) pandemic [Internet]. 2020. Available from: https://www.inclusion-europe.eu/coronavirus-pandemic/

23. Autism Europe. The autism community mobilizes itself to face COVID-19 [Internet]. 20 March. 2020 [cited 2020 Jun 30]. Available from: https://www.autismeurope.org/blog/2020/03/20/the-autism-community-mobilizes-itself-to-face-covid-19/

24. National Institute for Public Health and the Environment. Policy on testing for novel coronavirus disease (COVID-19) [Internet]. 2020. Available from: https://www.rivm.nl/en/node/154261

25. Sciensano. Hospital procedure for approaching a patient with possible/ confirmed COVID-19 [Internet]. 2020. Available from: https://covid-19.sciensano.be/sites/default/files/Covid19/COVID-19_procedure_hospitals_NL.pdf

26. UK Department of Health and Social Care. Coronavirus (COVID-19): getting tested [Internet]. 2020. Available from: https://www.gov.uk/guidance/coronavirus-covid-19-getting-tested

27. Buescher AVS, Cidav Z, Knapp M, Mandell DS. Costs of autism spectrum disorders in the United Kingdom and the United States. JAMA Pediatr [Internet]. 2014;168(8):721–8. Available from: https://www.scopus.com/inward/record.uri?eid=2-s2.0-84905180333&doi=10.1001%2Fjamapediatrics.2014.210&partnerID=40&md5=b3b7ee0eb6dcdcdc769d3bcf77bc90d7

28. Shinn AK, Viron M. Perspectives on the COVID-19 Pandemic and Individuals With Serious Mental Illness. J Clin Psychiatry. 2020 Apr;81(3).

29. World Health Organisation. Rational use of personal protective equipment for coronavirus disease 2019 (COVID-19) [Internet]. 2020. Available from: https://apps.who.int/iris/bitstream/handle/10665/331215/WHO-2019-nCov-IPCPPE_use-2020.1-eng.pdf

30. Organisation for Economic Development and Cooperation. OECD Policy Responses to Coronavirus (COVID-19) - Testing for COVID-19: A way to lift confinement restrictions [Internet]. 2020. Report No.: 4 May. Available from: https://www.oecd.org/coronavirus/policy-responses/testing-for-covid-19-a-way-to-lift-confinement-restrictions-89756248/#endnotea0z16

31. Health Protection Surveillance Centre. Interim Public Health, Infection Prevention & Control Guidelines on the Prevention and Management of COVID-19 Cases and Outbreaks in Residential Care Facilities [Internet]. 2020. Available from: https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/guidance/outbreakmanagementguidance/RCF guidance document.pdf

32. Uljarević M, Baranek G, Vivanti G, Hedley D, Hudry K, Lane A. Heterogeneity of sensory features in autism spectrum disorder: Challenges and perspectives for future research. Autism Res. 2017 May;10(5):703–10.

33. Boulter C, Freeston M, South M, Rodgers J. Intolerance of uncertainty as a framework for understanding anxiety in children and adolescents with autism spectrum disorders. J Autism Dev Disord [Internet]. 2014;44(6):1391–402. Available from: https://www.scopus.com/inward/record.uri?eid=2-s2.0-84901657139&doi=10.1007%2Fs10803-013-2001-x&partnerID=40&md5=b1b08e1fcac9cb9b18bbbccd9cac6104

34. European Centre for Disease Prevention and Control. Diagnostic testing and screening for SARS-CoV-2 [Internet]. 2020. Available from: https://www.ecdc.europa.eu/en/covid-19/latest-evidence/diagnostic-testing

35. Istituto Superiore di Sanità. Interim Indications for appropriate support of people on the autistic spectrum in the current emergency scenario SARS-CoV-2 [Internet]. 2020. Report No.: 30 March. Available from: vhttps://www.iss.it/documents/20126/0/Rapporto+ISS+COVID-19+n.+8+autismo+%282%29.pdf/c558b34e-1bc9-c868-0c75-0030f8299bca?t=1585757457709

36. Agency for Care and Health. Covid-19 - Mental health care [Internet]. 2020. Available from: https://www.zorg-en-gezondheid.be/corona-richtlijnen-voor-zorgprofessionals

37. European Disability Forum. Open letter to leaders at the EU and in EU countries: COVID-19 - disability inclusive response [Internet]. 13 March. 2020. Available from: http://edf-feph.org/newsroom/news/open-letter-leaders-eu-and-eu-countries-covid-19-disability-inclusive-response

38. NHS Providers. The impact of COVID-19 on mental health trusts in the NHS [Internet]. 2020. Available from: https://nhsproviders.org/media/689590/spotlight-on-mental-health.pdf

39. Council of Europe. Bioethics COVID-19: Selected resources by country [Internet]. 2020. Available from: https://www.coe.int/en/web/bioethics/selected-resources-by-

country/

40. Federation of Medical Specialists. Guidance: Triage home treatment versus referral to hospital in elderly patients with (suspected) COVID-19 [Internet]. 2020. (7 May). Report No.: 3. Available from: https://translate.google.com/translate?hl=en&sl=nl&u=https://www.demedischspecialist.nl/sites/default/files/Leidraad%2520triage%2520thuisbehandeling%2520versus%2520verwijzen%2520oudere%2520pati%25C3%25ABnt%2520met%2520verdenking%2520COVID-19.pdf&prev=search&pto=aue

41. Joebges S, Biller-Andorno N. Ethics guidelines on COVID-19 triage—an emerging international consensus. Crit Care [Internet]. 2020;24(1):201. Available from: https://doi.org/10.1186/s13054-020-02927-1

42. Ethics Working Group of the Austrian Society for Anaesthesiology Resuscitation and Intensive Care. Allocation of intensive care medical resources: Occasion of the Covid 19 pandemic [Internet]. 2020. Available from: https://www.oegari.at/web_files/cms_daten/covid-19_ressourcenallokation_gari-statement_v1.7_final_2020-03-17.pdf

43. Austria Bioethics Commission. Management of scarce resources in healthcare in the context of the COVID-19 pandemic: Opinion of the Bioethics Commission [Internet]. 2020. Available from: https://rm.coe.int/management-scarce-resources/16809e40f1

44. Azoulay É, Beloucif S, Guidet B, Pateron D, Vivien B, Le Dorze M. Admission decisions to intensive care units in the context of the major COVID-19 outbreak: local guidance from the COVID-19 Paris-region area. Crit Care [Internet]. 2020;24(1):293. Available from: https://doi.org/10.1186/s13054-020-03021-2

45. German Interdisciplinary Association for Intensive Care and Emergency Medicine. Decisions on the allocation of intensive care medicine resources in the context of the COVID-19 pandemic (Version 2) [Internet]. 2020. Available from: https://www.awmf.org/uploads/tx_szleitlinien/040-013l_S1_Zuteilung-intensivmedizinscher-Ressourcen-COVID-19-Pandemie-Klinisch-ethische_Empfehlungen_2020-04.pdf

46. Department of Health Ireland. Ethical Framework for Decision-Making in a Pandemic [Internet]. 2020. Available from: https://www.gov.ie/en/publication/dbf3fb-ethical-framework-for-decision-making-in-a-pandemic/

47. Italian Society of Anaesthesia Analgesia Resuscitation and Intensive Care. Clinical Ethics Recommendations for the Allocation of Intensive Care Treatments in exceptional, resource-limited circumstances - Version n. 1 Posted on March, 16. 2020;1–8.

48. Clarfield AM, Dwolatzky T, Brill S, Press Y, Glick S, Shvartzman P, et al. Israel Ad Hoc COVID-19 Committee: Guidelines for Care of Older Persons During a Pandemic. J Am Geriatr Soc [Internet]. 2020;11 May. Available from: https://doi.org/10.1111/jgs.16554

49. Cassidy SA, Nicolaidis C, Davies B, Rosa SDR, Eisenman D, Onaiwu MG, et al. An Expert Discussion on Autism in the COVID-19 Pandemic. Autism in Adulthood [Internet]. 2020 May 8;2(2):106–17. Available from: https://doi.org/10.1089/aut.2020.29013.sjc

50. Health Service Journal. Learning disabilities patients told they may be 'too frail' for mechanical ventilation if they get covid-19 [Internet]. 4 April. 2020. Available from: https://www.hsj.co.uk/coronavirus/learning-disabilities-patients-told-they-may-be-too-frail-for-mechanical-ventilation-if-they-get-covid-19/7027318.article

51. Tavernor L, Barron E, Rodgers J, Mcconachie H. Finding out what matters: Validity of quality of life measurement in young people with ASD. Child Care Health Dev. 2013;39(4):592–601.

52. Hodge and Allen Solicitors. NICE amends COVID-19 critical care guidelines after judicial review challenge [Internet]. Vol. 31 March. 2020. Available from: https://www.hja.net/press-releases/nice-amends-covid-19-critical-care-guideline-after-judicial-review-challenge/

53. Mencap. Mencap responds to new NICE COVID-19 guidance [Internet]. 02 April. 2020. Available from: https://www.mencap.org.uk/press-release/mencap-responds-deeply-troubling-new-nice-covid-19-guidance

54. National Institute of Health and Care Excellence. COVID-19 rapid guideline: critical care in adults [Internet]. 2020. Report No.: 20 March. Available from: https://www.nice.org.uk/guidance/ng159/resources/covid19-rapid-guideline-critical-care-in-adults-pdf-66141848681413

55. Montgomery J, Stokes-Lampard HJ, Griffiths MD, Gardiner D, Harvey D, Suntharalingam G. Assessing whether COVID-19 patients will benefit from critical care, and an objective approach to capacity challenges during a pandemic: An Intensive Care Society clinical guideline. J Intensive Care Soc [Internet]. 2020 Aug 17;1751143720948537. Available from: https://doi.org/10.1177/1751143720948537

56. NVAVG. Guidance referral of the adult patient with an intellectual disability and (suspected) COVID-19 [Internet]. 2020. Report No.: 15 April. Available from: https://translate.googleusercontent.com/translate_c?depth=1&hl=en&prev=search&pto=aue&rurl=translate.google.com&sl=nl&sp=nmt4&u=https://nvavg.nl/wp-content/uploads/2020/04/NVAVG_Covid-19_leidraad.pdf&usg=ALkJrhjFUhRYRyvgthG2T1ECCGY-7qvnaA

57. Royal Dutch Medical Association. Scenario Triage based on non-medical considerations for IC inclusion at the time of phase 3 in the COVID-19 pandemic [Internet]. 2020. Available from: https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/publicaties/2020/06/16/draaiboek-triage-op-basis-van-niet-medische-overwegingen-voor-ic-opname-ten-tijde-van-fase-3-in-de-covid-19-pandemie/draaiboek-triage-op-basis-van-niet-medische-overwegingen-voor-ic-opname-ten-tijde-van-fase-3-in-de-covid-19-pandemie.pdf

58. The Spanish Society of Intensive Critical Medicine and Coronary Units. Plan de contingencia para loc servicios de medicina intensiva frente a la pandemia COVID-19 [Internet]. 2020. Available from: https://www.semicyuc.org/covid19_files/Plan_de_Contingencia_COVID-19.pdf

59. Devereaux A V, Dichter JR, Christian MD, Dubler NN, Sandrock CE, Hick JL, et al. Definitive Care for the Critically Ill During a Disaster: A Framework for Allocation of Scarce Resources in Mass Critical Care: From a Task Force for Mass Critical Care Summit Meeting, January 26–27, 2007, Chicago, IL. Chest [Internet]. 2008

May 1;133(5):51S–66S. Available from: https://doi.org/10.1378/chest.07-2693

60. Biddison LD, Berkowitz KA, Courtney B, De Jong CMJ, Devereaux A V, Kissoon N, et al. Ethical Considerations: Care of the Critically Ill and Injured During Pandemics and Disasters: CHEST Consensus Statement. Chest [Internet]. 2014 Oct 1;146(4):e145S–e155S. Available from: https://doi.org/10.1378/chest.14-0742

61. Spanish Bioethics Committee. Report of the Spanish Bioethics Committee on bioethics aspects of the prioritisation of sanitary resources in the context of the coronavirus crisis [Internet]. 2020. Available from: http://assets.comitedebioetica.es/files/documentacion/Informe CBE- Priorizacion de recursos sanitarios-coronavirus CBE.pdf

62. Spanish Ministry of Health. Ministry of Health report on ethical issues in pandemic situations: SARS-CoV-2 [Internet]. 2020. Report No.: 3 April. Available from: https://rm.coe.int/pandemic-covid-19-spain-eng/16809e3a78

63. Arango C. Lessons Learned From the Coronavirus Health Crisis in Madrid, Spain: How COVID-19 Has Changed Our Lives in the Last 2 Weeks. Biol Psychiatry [Internet]. 2020 Apr 8;S0006-3223(20)31493-1. Available from: https://pubmed.ncbi.nlm.nih.gov/32381276

64. Autism Spain. Autism Spain prepares a document of de-escalation proposals for entities and services specialized in people with autism and their families [Internet]. 2020. Available from: http://www.autismo.org.es/actualidad/articulo/autismo-espana-elabora-un-documento-de-propuestas-de-desescalada-para-entidades

65. NHS Digital. Autism Statistics [Internet]. 2019. Available from: https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics/autism-statistics

66. European Association of Service providers for Persons with Disabilities. The impact of COVID-19 on disability services in Europe [Internet]. 2020. Available from: https://www.easpd.eu/sites/default/files/sites/default/files/Publications2020/impact_of_covid-19_on_disability_services_in_europe_a_first_snapshot.pdf

67. National Institute for Health and Disability Insurance. Medical care and benefits insurance: exceptional measures to combat COVID 19 [Internet]. 2020. Available from: https://www.riziv.fgov.be/nl/covid19/Paginas/default.aspx

68. Social Care Institute for Excellence. Understanding the impact of COVID-19 responses on citizens [Internet]. 2020. Available from: https://www.scie.org.uk/care-providers/coronavirus-covid-19/commissioning/impact-on-citizens

69. Cautreels M, Heiremans M. Corona pushes disabled care into the corner where the blows fall [Internet]. 2020. Available from: https://sociaal.net/opinie/corona-duwt-gehandicaptenzorg-in-hoek-waar-de-klappen-vallen/

70. Ministry of Health Wellbeing and Sports. New visitors scheme for care for the disabled and mental health care [Internet]. 2020. Available from: https://www.rijksoverheid.nl/onderwerpen/coronavirus-covid-19/nieuws/2020/03/23/nieuwe-bezoekersregeling-gehandicaptenzorg-en-ggz

71. European Centre for Disease Prevention and Control. Surveillance of COVID-19 at longterm care facilities in the EU/EEA [Internet]. 2020. Available from:

https://www.ecdc.europa.eu/sites/default/files/documents/covid-19-long-term-care-facilities-surveillance-guidance.pdf

72. UK Department of Health and Social Care. Update on policies for visiting arrangements in care homes [Internet]. 2020. Report No.: 31 July. Available from: https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus/update-on-policies-for-visiting-arrangements-in-care-homes

73. UK Department of Health and Social Care. Care Act easements: guidance for local authorities [Internet]. 2020. Available from: https://www.gov.uk/government/publications/coronavirus-covid-19-changes-to-the-care-act-2014/care-act-easements-guidance-for-local-authorities#purpose-of-the-easements

74. Care Quality Commission. The Care Act and the 'easements' to it [Internet]. 2020. Available from: https://www.cqc.org.uk/guidance-providers/adult-social-care/care-act-easements-it

75. Hodgson K, Grimm F, Vestesson E, Brine R, Deeny S. Briefing: Adult social care and COVID-19 Assessing the impact on social care users and staff in England so far [Internet]. 2020. Report No.: July. Available from: https://www.health.org.uk/publications/reports/adult-social-care-and-covid-19-assessing-the-impact-on-social-care-users-and-staff-in-england-so-far

76. Mencap. Coronavirus: Information about going to hospital [Internet]. 2020. Available from: https://www.mencap.org.uk/advice-and-support/coronavirus-covid-19/coronavirus-information-about-going-hospital

77. Widgit. Critical Care Covid-19 Communication Chart [Internet]. 2020. Available from: https://www.widgit.com/products/health/covid19-communication-chart.htm

78. NHS England. COVID-19 Grab and Go Guide - Form [Internet]. 2020. Available from: https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0381-nhs-covid-19-grab-and-go-lda-form.pdf

79. House of Lords Hansard. Covid-19: Social Care Services [Internet]. Vol. 803. 2020. Available from: https://hansard.parliament.uk/Lords/2020-04-23/debates/0D93005E-2D8C-4994-98A0-AABD6341841A/Covid-19SocialCareServices?highlight=covid#contribution-872EF5DC-BE3B-4042-9C19-723E54CB19E8

80. NHS England. Clinical guide for front line staff to support the management of patients with a learning disability, autism or both during the coronavirus pandemic – relevant to all clinical specialities [Internet]. 2020. Report No.: 24 March Version 1. Available from: https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0031_Specialty-guide_LD-and-coronavirus-v1_-24-March.pdf

81. World Health Organization. COVID-19 Strategy Update 4th April 2020 [Internet]. 2020. Available from: https://www.who.int/docs/default-source/coronaviruse/covid-strategy-update-14april2020.pdf?sfvrsn=29da3ba0_19

82. European Commission. Testing kits for COVID-19: What is the EU doing? [Internet]. 2020. Available from: https://ec.europa.eu/health/sites/health/files/preparedness_response/docs/testingkits_fa

ctsheet.pdf

83. European Centre for Disease Prevention and Control. An overview of the rapid test situation for COVID-19 diagnosis in the EU / EEA [Internet]. 2020. Available from: https://www.ecdc.europa.eu/sites/default/files/documents/Overview-rapid-test-situation-for-COVID-19-diagnosis-EU-EEA.pdf

84. European Commission. COVID-19 EU recommendations for testing strategies. 2020.

85. DuBois D, Ameis S, Lai M-C, Casanova M, Desarkar P. Interoception in Autism Spectrum Disorder: A Review. Int J Dev Neurosci. 2016 Jun 1;52.

86. Kinnaird E, Stewart C, Tchanturia K. Investigating alexithymia in autism: A systematic review and meta-analysis. Eur psychiatry J Assoc Eur Psychiatr. 2019 Jan;55:80–9.

87. AsIAm. AsIAm and COVID-19. 2020.

88. Williams E, Bond K, Zhang B, Putland M, Williamson DA. Saliva as a non-invasive specimen for detection of SARS-CoV-2. J Clin Microbiol. 2020;50(April).

89. To KK-W, Tsang OT-Y, Leung W-S, Tam AR, Wu T-C, Lung DC, et al. Temporal profiles of viral load in posterior oropharyngeal saliva samples and serum antibody responses during infection by SARS-CoV-2: an observational cohort study. Lancet Infect Dis [Internet]. 2020 May 1;20(5):565–74. Available from: https://doi.org/10.1016/S1473-3099(20)30196-1

90. Pratt K, Baird G, Gringras P. Ensuring successful admission to hospital for young people with learning difficulties, autism and challenging behaviour: A continuous quality improvement and change management programme. Child Care Health Dev [Internet]. 2012;38(6):789–97. Available from: https://www.scopus.com/inward/record.uri?eid=2-s2.0-84867401412&doi=10.1111%2Fj.1365-2214.2011.01335.x&partnerID=40&md5=ad8a224830506d6d895daea3bda9a4c7

91. World Health Organisation. Strengthening the health system response to COVID-19 in the WHO transmission scenarios: Action points for the WHO European Region [Internet]. 2020. Report No.: 01 April. Available from: https://www.euro.who.int/__data/assets/pdf_file/0005/436352/strengthening-health-system-response-COVID-19-WHO-transmission-scenarios.pdf

92. Truog RD, Mitchell C, Daley GQ. The Toughest Triage — Allocating Ventilators in a Pandemic. N Engl J Med [Internet]. 2020 Mar 23;382(21):1973–5. Available from: https://doi.org/10.1056/NEJMp2005689

93. New York State Task Force on Life and the Law & New York State Department of Health. Ventilator Allocation Guidelines [Internet]. 2015. Report No.: November. Available from: https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf

94. European Court of Human Rights. European Convention on Human Rights [Internet]. Strasbourg; 2010. Available from: https://www.echr.coe.int/Documents/Convention_ENG.pdf

95. United Nations. Convention on the rights of persons with disabilities. 2008.

96. International Disability Alliance. An Open Letter to the World Health Organisation [Internet]. 2020. Available from: http://www.internationaldisabilityalliance.org/sites/default/files/ida_letter_to_who_march_31_2020.pdf

97. Grote H, Izagaren F. Covid-19: The communication needs of D/deaf healthcare workers and patients are being forgotten. BMJ. 2020 Jun;369:m2372.

98. Thomson S, Figueras J, Evetovits T, Jowett M, Mladovsky P, Maresso A, et al. Economic crisis, health systems and health in Europe: impact and implications for policy [Internet]. 2014. Available from: https://www.euro.who.int/__data/assets/pdf_file/0008/257579/Economic-crisis-health-systems-Europe-impact-implications-policy.pdf?ua=1

99. Smith E, Kenny L, Harper G, Bradshaw J, Chesterman E, Shorthouse J, et al. Action Briefing: Social Care. 2020.

100. Galletly C. Psychiatry in the COVID-19 Era. Aust New Zeal J Psychiatry [Internet]. 2020 May 1;54(5):447–8. Available from: https://doi.org/10.1177/0004867420920359

101. Vieta E, Pérez V, Arango C. Psychiatry in the aftermath of COVID-19. Rev Psiquiatr y Salud Ment [Internet]. 2020; Available from: http://www.sciencedirect.com/science/article/pii/S188898912030029X

102. Sutherland R, Trembath D, Roberts J. Telehealth and autism: A systematic search and review of the literature. Int J Speech Lang Pathol. 2018 Jun;20(3):324–36.

103. Little LM, Wallisch A, Pope E, Dunn W. Acceptability and Cost Comparison of a Telehealth Intervention for Families of Children With Autism. Infants Young Child [Internet]. 2018;31(4). Available from: https://journals.lww.com/iycjournal/Fulltext/2018/10000/Acceptability_and_Cost_Comparison_of_a_Telehealth.3.aspx

104. European Commission. Strategic Plan 2016-2020: DG Health and Food Safety [Internet]. 2017. Available from: https://ec.europa.eu/info/sites/info/files/strategic-plan-2016-2020-dg-sante_en_0.pdf

105. Office of the Federal Council for the Mental Health Professions. Mental Health Care provided remotely by GGZ-professionals in the context of the Covid-19quarantine measures [Internet]. 2020. Available from: https://overlegorganen.gezondheid.belgie.be/sites/default/files/documents/20200401-bureaufrggzb-nota_nl_covid-19.pdf

106. Ameis SH, Lai M-C, Mulsant BH, Szatmari P. Coping, fostering resilience, and driving care innovation for autistic people and their families during the COVID-19 pandemic and beyond. Mol Autism [Internet]. 2020;11(1):61. Available from: https://doi.org/10.1186/s13229-020-00365-y

107. Noel K, Ellison B. Inclusive innovation in telehealth. npj Digit Med [Internet]. 2020;3(1):89. Available from: https://doi.org/10.1038/s41746-020-0296-5

108. Autistica. Coronavirus and autism [Internet]. 2020. Available from: https://www.autistica.org.uk/what-is-autism/coronavirus

109. Pearcey S, Shum A, Waite P, Creswell C. Supplementary Report 03: Differences in pandemic anxiety, parent/carer stressors and reported needs between parent/carers of

children with and without ASD; Change over time in mental health for children with ASD. [Internet]. 2020. Available from: https://emergingminds.org.uk/wp-content/uploads/2020/07/Co-SPACE-supplementary-report-03-final.pdf

110. White LC, Law JK, Daniels AM, Toroney J, Vernoia B, Xiao S, et al. Brief Report: Impact of COVID-19 on Individuals with ASD and Their Caregivers: A Perspective from the SPARK Cohort. J Autism Dev Disord. 2021 Jan;

111. Summers J, Baribeau D, Mockford M, Goldhopf L, Ambrozewicz P, Szatmari P, et al. Supporting Children With Neurodevelopmental Disorders During the COVID-19 Pandemic. Vol. 60, Journal of the American Academy of Child and Adolescent Psychiatry. United States; 2021. p. 2–6.

112. Asadi-Pooya AA, Simani L. Central nervous system manifestations of COVID-19: A systematic review. J Neurol Sci. 2020 Jun;413:116832.

113. D'Agostino A, Demartini B, Cavallotti S, Gambini O. Mental health services in Italy during the COVID-19 outbreak. The Lancet Psychiatry [Internet]. 2020 May 1;7(5):385–7. Available from: https://doi.org/10.1016/S2215-0366(20)30133-4

114. European Parliament. Health Care Systems in the EU: A Comparative Study [Internet]. 1998. Available from: https://www.europarl.europa.eu/workingpapers/saco/pdf/101_en.pdf

115. Robertson R, Gregory S, Jabbal J. The social care and health systems of nine countries [Internet]. 2014. Available from: https://www.kingsfund.org.uk/sites/default/files/media/commission-background-paper-social-care-health-system-other-countries.pdf

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, LG and DM led on the study concept and development. MD, PV and AW provided additional study sources. All authors critically reviewed the manuscript and agreed on submission.

Acknowledgements

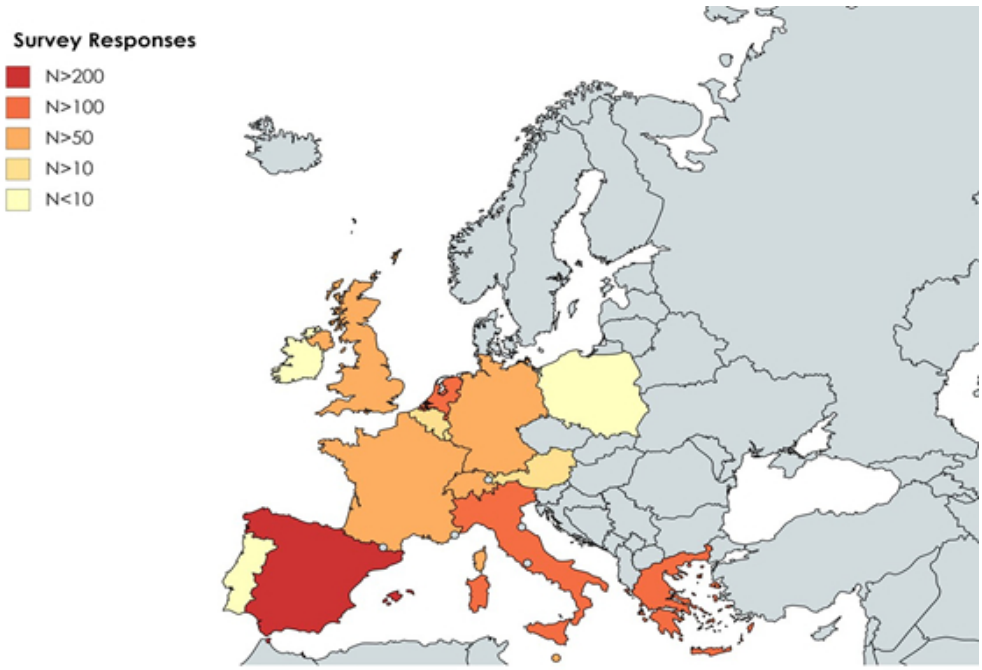
We would like to thank the AIMS-2-TRIALS Clinical Trials Network and Early Career Researchers in Autism Network for their contributions and support for this project. We particularly acknowledge: Roderik Plas, Katrien van den Bosch, Evdokia Anagnostou, Kathrin Hippler, Sonja Metzler, Sofie Boterberg, Herbert Roeyers, Guillame Dumas, Frédérique Bonnet-Brilhault, Louise Poutska, Christine Freitag, Filippo Muratori, Eugenia Conti, Erik Mulder, Giorgia Bussu, Anne Smit, Elke de Jonge, Manon Krol, Ciara Molloy, Julia Koziel, Célia Rasga, Sonija Luzi, Monica Burdeus, Laura Gisbert, Antonia San José Cáceres, Eleni Kroupi, Covadonga Martinez, Alvaro Beja, Miriam Rivero Contreras, María Manzano Arjona, Clara Janisel Fernández Álvarez, Ruth Campos, Alicia Alcon, Jorge Lugo, Imanol Setien, Gara Arteaga, Ana Blazquez and Dominika Zofia Wojcik.

Data availability

All data relevant to the study are included in the article or uploaded as supplementary information. Should further details or materials be required, please contact the corresponding author.

Figure Caption

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.



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.

Supplementary Table 1

Autism-Europe survey demographics, collected between April 7th and May 31st 2020.

		N respondent autistic person				*N* respondent caregiver				Gender
		Age range 0-18	Age range 19-40	Age range 41-64	Age range 65+	Age range 0-18	Age range 18-40	Age range 41-65	Age range 65+	M:F:NB[a]
Region	Austria	0	4	1	0	5	1	1	0	7:4:0
	Belgium	1	9	9	0	3	4	8	0	11:21:0
	France	0	21	9	1	13	12	26	4	30:52:1
	Germany	1	25	12	1	3	8	9	1	12:45:1
	Greece	1	4	1	0	6	46	107	0	24:127:0
	Ireland	0	2	1	0	1	0	1	0	2:3:0
	Italy	4	4	6	0	12	30	122	14	64:122:1
	Luxembourg	0	11	3	0	3	1	12	3	14:17:0
	Malta	0	1	0	0	11	23	16	1	8:33:0
	Netherlands	7	45	46	1	4	10	30	0	34:103:2
	Poland	0	1	0	0	0	1	0	1	0:3:0
	Portugal	0	0	0	0	0	0	0	1	0:1:0
	Spain	1	10	2	0	27	61	192	11	94:200:1
	Switzerland	3	34	19	1	16	17	53	1	47:95:1
	United Kingdom	2	18	23	1	1	6	13	2	16:42:4

Note: Age ranges and gender refer to the autistic person reporting, or being reported on by a caregiver. [a]M=Male; F=Female; NB=Non-binary/ third gender.

Supplementary Material 1

Common review templates for COVID-19 health and social care policies/ guidelines, distributed to the: a) AIMS-2-TRIALS early career autism researchers and panel of representatives from the autism community and; b) AIMS-2-TRIALS Clinical Trials Network.

a)

Enter: Country/ Region					
Source	**Summary of evidence**				
Full source reference (include date and weblink, where relevant)	**Access to COVID-19 screening/ testing**	**Hospitalisation/ intensive care**	**Social care/ self-isolation**	**Changes to usual healthcare practice**	**Other comments/ issues** **OR** **Review**
Include publication date and, where relevant, the full weblink.	Consider: test availability; test procedure (e.g. sensory); getting test results; any other issues.	Consider: availability of hospital/ intensive care beds; triage/ resource allocation; inclusion/ exclusion criteria; provision and quality of care; resuscitation orders; discharge procedures; any other issues.	Consider: provision of social/ residential/ community care; support for individuals who are self-isolating or shielding; any other issues.	Consider: access to/ delivery of standard services (e.g. mental health, remote delivery).	Any other comments, notes, guidelines, policies. OR Professional commentary on changes to regional services/ official guidance on service access (for AIMS-2-TRIALS Clinical Trials Network).

Supplementary Table 2.

List of published policies/ guidelines included in this study, with source of access documented.

Publication	Date	Language	Source of access
Belgium			
National Public Health Institute (Sciensano)	20/05/2020	Dutch	https://covid-19.sciensano.be/sites/default/files/Covid19/COVID-19_procedure_hospitals_NL.pdf
Ethics committee for care in UZ Leuven	17/03/2020	Dutch	https://cdn.digisecure.be/grip/2020331121514529_leidraad-voor-ethisch-handelen-uz-leuven.pdf
Belgian Society of Intensive Care Medicine	18/03/2020	English	https://www.hartcentrumhasselt.be/professioneel/nieuws-professioneel/ethical-principles-concerning-proportionality-of-critical-care-during-the-covid-19-pandemic-advice-by-the-belgian-society-of-ic-medicine%20
Federal Public Service Social Security	29/05/2020	Dutch	https://www.socialsecurity.be/citizen/nl/static/infos/coronavirus/index.htm# https://www.socialsecurity.be/citizen/nl/static/infos/coronavirus/index.htm#
Agency for Care and Health	18/03/2020	Dutch	https://www.zorg-en-gezondheid.be/sites/default/files/atoms/files/maatregelen%20COVID_19_GGZ_200318.pdf
FPS Public Health, Food Chain Safety and Environment of Belgium	01/04/2020	Dutch	https://overlegorganen.gezondheid.belgie.be/sites/default/files/documents/20200401-bureaufrggzb-nota_nl_covid-19.pdf
Department of Welfare, Public Health and Family	13/04/2020	Dutch	https://www.departementwvg.be/sites/default/files/media/20200414_Taskforce_wob.pdf
Belgium Society of Emergency and Disaster Medicine and the Belgian Resuscitation Council	22/03/2020	English	https://www.ordeartsenbrabant.org/assets/images/BESEDIM_26mars2020_Ethical-decision-making-in-emergencies_COVID19_22032020_final.pdf
Flemish Agency for Persons with a Disability	21/04/2020	Dutch	https://www.vaph.be/sites/default/files/documents/15117/infonota_20_102_compenserende_maatregelen_nav_covid-19_7_.pdf
Flemish Agency for Persons with a Disability	15/04/2020	Dutch	https://www.vaph.be/nieuws/de-impact-van-de-coronacrisis-op-personen-met-een-verstandelijke-handicap-enof
National Employment Office	01/07/2020	Dutch/German/French	https://www.rva.be/nl/documentatie/infoblad/t9-0#h2_0
Agency for Care and Health	17/03/2020	Dutch	https://www.zorg-en-gezondheid.be/sites/default/files/atoms/files/Maatregelen_corona_RCA_17_03_20.pdf
Fédération Wallonie-Bruxelles	17/03/2020	French	http://www.enseignement.be/index.php?page=28294
National Institute for Health and Disability Insurance	N/A	Dutch	https://www.riziv.fgov.be/nl/covid19/Paginas/default.aspx

The Netherlands			
Ministry of Health, Wellbeing and Sports	23/03/2020	Dutch	https://www.rijksoverheid.nl/onderwerpen/coronavirus-covid-19/zorg/geestelijke-gezondheidszorg-ggz https://www.rijksoverheid.nl/onderwerpen/coronavirus-covid-19/nieuws/2020/03/23/nieuwe-bezoekersregeling-gehandicaptenzorg-en-ggz
National Institute for Public Health and the Environment	17/08/2020	Dutch	https://lci.rivm.nl/covid-19/PBMbuitenziekenhuis
Dutch Youth Institute	19/08/2020	Dutch	https://www.nji.nl/nl/coronavirus/Professionals/Fysiek-contact-bij-ambulante-hulpverlening-bij-het-coronavirus
Federation of Medical Specialists		Dutch	https://www.demedischspecialist.nl/sites/default/files/Leidraad%20triage%20thuisbehandeling%20versus%20verwijzen%20oudere%20pati%C3%ABnt%20met%20verdenking%20COVID-19.pdf
Association of Mental Health Physicians	14/04/2020	Dutch	https://nvavg.nl/wp-content/uploads/2020/04/NVAVG_Covid-19_leidraad.pdf
Royal Dutch Medical Association	16/06/2020	Dutch	https://www.rijksoverheid.nl/documenten/publicaties/2020/06/16/draaiboek-triage-op-basis-van-niet-medische-overwegingen-voor-ic-opname-ten-tijde-van-fase-3-in-de-covid-19-pandemie
United Kingdom			
UK Department of Health and Social Care	12/08/2020	English	https://www.gov.uk/guidance/coronavirus-covid-19-getting-tested
NHS England		English	https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0290_Supporting-patients-who-are-unwell-with-COVID-19-in-MHLDA-settings.pdf
NHS Providers	03/06/2020	English	https://nhsproviders.org/media/689590/spotlight-on-mental-health.pdf
Health Protection Surveillance Centre	28/07/2020	English	https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/guidance/outbreakmanagementguidance/RCF guidance document.pdf
Social Care Institute for Excellence	29/06/2020	English	https://www.scie.org.uk/care-providers/coronavirus-covid-19/commissioning/impact-on-citizens
National Institute of Health and Care Excellence	20/03/2020	English	https://www.nice.org.uk/guidance/ng159/resources/covid19-rapid-guideline-critical-care-in-adults-pdf-66141848681413
UK Department of Health and Social Care	31/07/2020	English	https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus/update-on-policies-for-visiting-arrangements-in-care-homes https://www.gov.uk/government/publications/coronavirus-covid-19-changes-to-the-care-act-2014/care-act-easements-guidance-for-local-authorities#purpose-of-the-easements
Care Quality Commission	03/07/2020	English	https://www.cqc.org.uk/guidance-providers/adult-social-care/care-act-easements-it
Italy			
Osservatorio Nazionale Autismo ISS, Istituto Superiore di Sanità	30/03/2020	Italian	https://www.iss.it/documents/20126/0/Rapporto+ISS+COVID-19+n.+8+autismo+%282%29.pdf/c558b34e-1bc9-c868-0c75-0030f8299bca?t=1585757457709
Italian Society of Anaesthesia Analgesia Resuscitation and Intensive Care	?	Italian	http://www.siaarti.it/SiteAssets/News/COVID19%20-%20documenti%20SIAARTI/SIAARTI%20-%20Covid-19%20-%20Clinical%20Ethics%20Reccomendations.pdf
Germany			

Ethics Working Group of the Austrian Society for Anaesthesiology Resuscitation and Intensive Care	17/03/2020	German	https://www.oegari.at/web_files/cms_daten/covid-19_ressourcenallokation_gari-statement_v1.7_final_2020-03-17.pdf
Austria Bioethics Commission	31/03/2020	German	https://rm.coe.int/management-scarce-resources/16809e40f1
German Interdisciplinary Association for Intensive Care and Emergency Medicine	17/04/2020	German	https://www.awmf.org/uploads/tx_szleitlinien/040-013l_S1_Zuteilung-intensivmedizinscher-Ressourcen-COVID-19-Pandemie-Klinisch-ethische_Empfehlungen_2020-07_2.pdf
Ireleand			
Department of Health Ireland	27/03/2020	English	https://www.gov.ie/en/publication/dbf3fb-ethical-framework-for-decision-making-in-a-pandemic/
European guidelines			
Council of Europe	N/A	Various languages	https://www.coe.int/en/web/bioethics/selected-resources-by-country/
European Centre for Disease Prevention and Control	19/05/2020	English	https://www.ecdc.europa.eu/sites/default/files/documents/covid-19-long-term-care-facilities-surveillance-guidance.pdf
European Association of Service providers for Persons with Disabilities	04/2020	English	https://www.easpd.eu/sites/default/files/sites/default/files/Publications2020/impact_of_covid-19_on_disability_services_in_europe_a_first_snapshot.pdf
World Health Organisation	23/04/2020	English	https://www.euro.who.int/en/health-topics/health-emergencies/coronavirus-covid-19/statements/statement-invest-in-the-overlooked-and-unsung-build-sustainable-people-centred-long-term-care-in-the-wake-of-covid-19
Spain			
The Spanish Society of Intensive Critical Medicine and Coronary Units.	14/03/2020	Spanish	https://www.semicyuc.org/covid19_files/Plan_de_Contingencia_COVID-19.pdf
Spanish Bioethics Committee	23/03/2020	Spanish	http://assets.comitedebioetica.es/files/documentacion/Informe%20CBE-%20Priorizacion%20de%20recursos%20sanitarios-coronavirus%20CBE.pdf
Spanish Ministry of Health	03/04/2020	English	https://rm.coe.int/pandemic-covid-19-spain-eng/16809e3a78
Autism Spain	05/05/2020	Spanish	http://www.autismo.org.es/actualidad/articulo/autismo-espana-elabora-un-documento-de-propuestas-de-desescalada-para-entidades
France			
Ministry of Disability	04/05/2020	French	https://handicap.gouv.fr/IMG/pdf/04052020_-_les_grandes_lignes_du_plan_de_deconfinement_pour_les_personnes_en_situation_de_handicap_vd.pdf https://handicap.gouv.fr/autisme-et-troubles-du-neuro-developpement/infos-speciales-coronavirus/article/information-covid-19-et-confinement
President of the Republic	02/04/2020	French	https://www.elysee.fr/emmanuel-macron/2020/04/02/autisme https://www.gouvernement.fr/sites/default/files/contenu/piece-jointe/2020/03/ attestation-deplacement-falc.pdf

	17/03/2020		
Poland			
Organisation for the Help of Autistic People	06/04/2020	Polish	https://www.gdansk.pl/wiadomosci/sytuacja-osob-z-autyzmem-w-dobie-koronawirusa-rozmowa-z-malgorzata-rybicka,a,168209
National Fund for the Rehabilitation of Disabled People (PFRON)	02/03/2020	Polish	https://www.pfron.org.pl/aktualnosci/szczegoly-aktualnosci/news/pomoc-pfron-dla-osob-niepelnosprawnych-w-zwiazku-z-epidemia-koronawirusa/
Portugal			
The Portuguese Ministry of Health	18/04/2020	Portuguese	https://www.dgs.pt/directrizes-da-dgs/normas-e-circulares-normativas/norma-n-0112020-de-18042020-pdf.aspx

Supplementary Table 3

Autism-Europe survey items included in this review.

Autism-Europe survey items
Are you considered to be within the group at higher risk for COVID-19?
Were you tested for COVID-19? *If yes:* Did you receive adequate/ accessible information about getting tested for COVID-19? *If yes:* Were any reasonable adjustments provided for autism needs during testing for COVID-19?
Did you have to get treated in relation to COVID-19? *If yes:* Did you experience difficulty to contact healthcare professionals/ first aid responders during the COVID-19 spread? *If yes:* Was it due to the inaccessibility of the process e.g. contact to be made by phone?
Do you need support for daily activities? Have your usual support services been interrupted since the beginning of the COVID-19 spread?
Are your support person(s) considered at higher risk for COVID-19? If your support person(s) get(s) infected, do you have another support person?
Is there accessible information available for autistic people on the COVID-19 spread and the current measures in place where you live?
If you would like to make any comment, use the field below – optional.