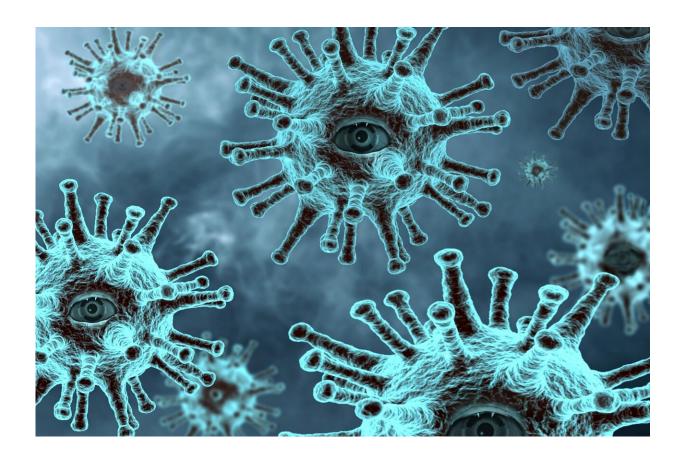


## Autistic people across Europe have struggled to access COVID-19 services during pandemic

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Autistic people across Europe have not only struggled to access standard health and care services during the pandemic, but, crucially, also those



for COVID-19, finds research published in the online journal BMJ Open.

The likely consequences of this widening of existing <u>health inequalities</u> for this community, will have been to increase associated deaths, ill health, behavioural issues and poor quality of life, warn the authors.

Amid concerns that the pandemic had excluded some vulnerable groups from health and care services, the researchers reviewed the regional and national policies and guidelines of 15 European Union countries on access to COVID-19 treatment for autistic people, published between March and July 2020.

They looked specifically at autistic people's access to COVID-19 testing; provisions for hospital and <u>intensive care treatment</u>; and changes to standard health and social care services.

They also analysed survey data from Autism-Europe on the lived experiences of 1301 autistic people and caregivers in the included countries: Spain; Italy; Greece; the Netherlands; Switzerland; France; the UK; Germany; Malta; Belgium; Luxembourg; Austria; Ireland; Poland; and Portugal.

The findings showed that autistic people experienced significant barriers when accessing COVID-19 services.

Despite being at heightened risk of serious illness, if infected with <u>coronavirus</u>, because of co-existing <u>health conditions</u>, autistic people weren't prioritised for COVID-19 testing.

The authors point out that between 5% and 25% of autistic people live in residential care, with up to a further 27% living in supported accommodation, where transmission rates were high in the first wave of the pandemic.



Even in countries where those with underlying conditions and those living in 'high risk' settings were prioritised for access to testing, there was no guidance for those living in supported accommodation and the community.

Nor was there any guidance on enhancing the tolerability (and therefore accessibility) of test procedures for autistic people, many of whom have sensory sensitivities around swabbing, for example, and don't cope well with changes to their routine, such as visiting unfamiliar test sites, note the researchers.

Second, many COVID-19 outpatient and inpatient treatment services were extremely hard to access, largely because of <u>individual differences</u> in communication needs—access to use phone services, for example.

Third, intensive care unit triage protocols in many European countries directly or indirectly excluded autistic people from life-saving treatments.

Many of these protocols require 'frailty assessments' which refer to an individual's dependency on others for assistance with daily care needs and personal care.

While the unsuitability of these assessments for autistic people was recognised in some countries, including in the UK and the Netherlands, measures to prevent the misapplication of frailty and cognitive function assessments haven't been implemented systematically across European countries, note the researchers.

Finally, abrupt interruptions to standard health and social care with no mitigating measures in place left over 70% of autistic people without everyday support, the survey responses showed.



Around a third of those surveyed said they required daily support (35%; 451) and another third said they required occasional support with routine activities of daily living (33%; 431).

Many services were already stretched before the pandemic, including autism diagnostic services, for which average waiting times can be well over a year, while many community services for autistic people were forced to close, say the authors.

In light of their findings, they make a raft of policy and clinical practice recommendations to reduce health and social care inequalities for autistic people across Europe during public health emergencies.

These "require particularly urgent consideration to enhance the future care of <u>autistic people</u> both during and beyond the pandemic," they conclude.

**More information:** Bethany Oakley et al, COVID-19 health and social care access for autistic people: European policy review, *BMJ Open* (2021). DOI: 10.1136/bmjopen-2020-045341

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