

ACCESS-EU

Autistic people's experience of service access in Europe

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Introduction

Autistic people depend on a variety of services, yet many report difficulties accessing them. Previous research demonstrates that autistic people experience challenges when accessing services including a lack of services, multiple barriers to access [1, 2], long waiting times [3], stigma and discrimination [4, 5], greater financial burden [6] and lack of autism expertise among service providers [7].

ACCESS-EU is a research project exploring autistic people's experiences of service access across Europe including a wide range of services from physical and mental health services to education and social care.

The survey included questions on:

- **Successful and unsuccessful attempts at service access**
- **Waiting times**
- **Barriers that people experienced when trying to access services**

Participants included autistic people living in Europe (aged 16 and over) and family carers of autistic people (including children and adults) who completed the survey on behalf of their autistic family members.

The survey was open from May 2020 to May 2022 and was available in English, Spanish, German, French, Polish, Italian, Slovenian and Czech.

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Sample Details

This report includes data from 2,322 formally diagnosed autistic people across Europe, including both children and adults. The majority of the data was collected from people in the UK, Spain, Germany, France, and Poland, with some representation from other countries in Europe.

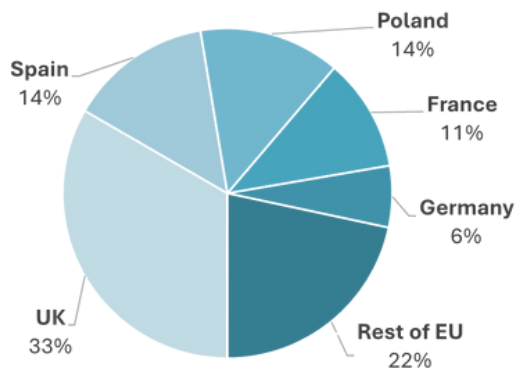
42% of responses were completed by autistic people aged 16 and over. 58% of responses were completed by family carers on behalf of an autistic person (including all responses for those aged under 16 years).

The average age of autistic people represented in the survey was 26 years old, with the youngest being one year old and the oldest 78 years old. Almost two-thirds (65%) of autistic people represented (either by self-report or parent report) were adults, and a third (35%) were children below the age of 16.

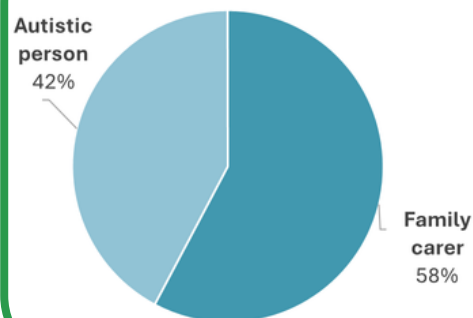
62% of the sample were male, 33% were female, and 5% were other-identifying.

81% of people reported a diagnosis of a co-occurring mental or physical health condition. With the most reported co-occurring conditions being anxiety disorders (31%), digestive problems (25%), intellectual disability, learning disability, or global developmental delay (25%).

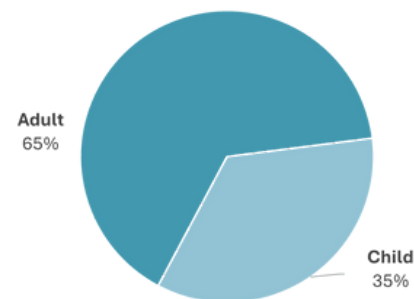
Country contribution



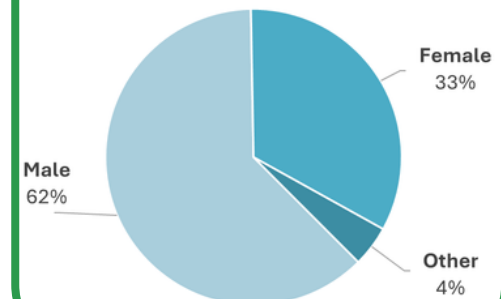
Respondent



Age group



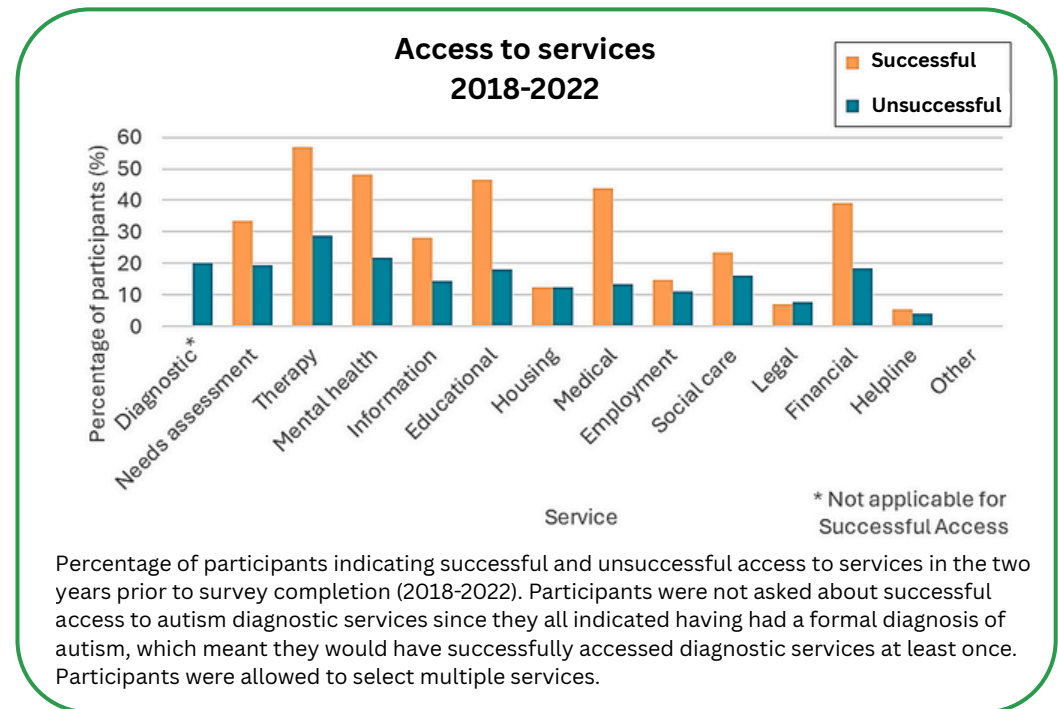
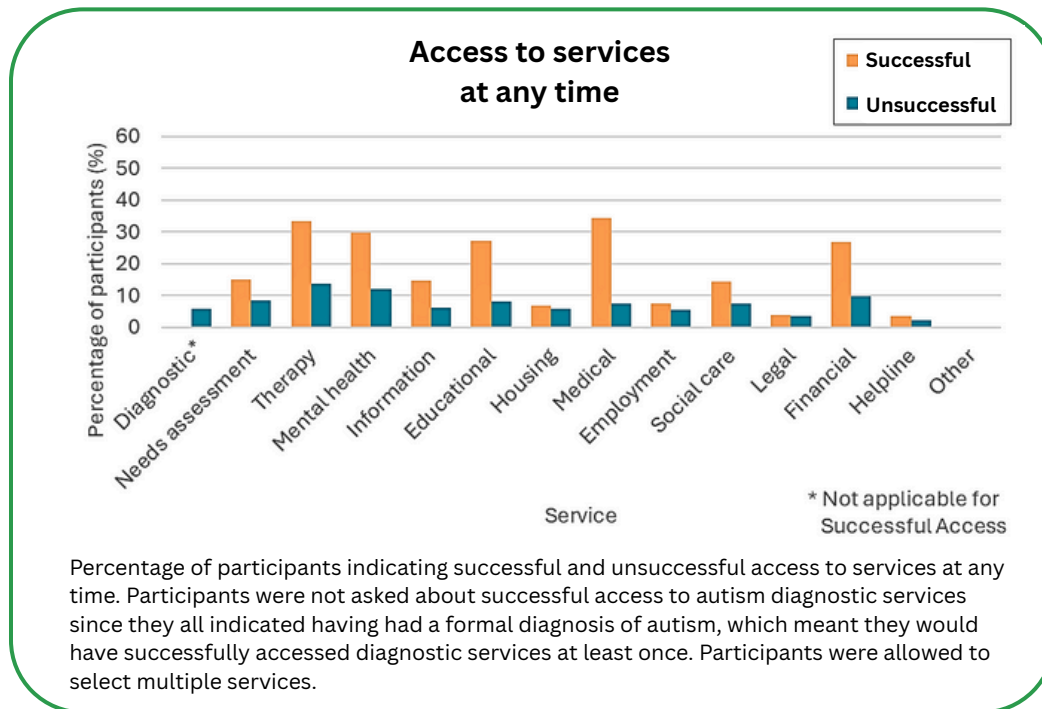
Gender



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Service Access Results

Overall, access to services was **inconsistent**; participants reported successfully accessing services at certain times, but not at others. These results were seen for attempts at service access made at any time prior to the survey completion, as well as within two years prior to survey completion (including years 2018-2022).



For the period two years prior to survey completion (2018-2022), the services where the most people reported at least one successful attempt at accessing were **medical (34%), therapy (33%), mental health (30%), educational (27%) and financial (27%) services**. The services where the most people reported at least one failed attempt at access in this period were **therapy (14%), mental health (12%), financial (10%), needs assessment (8%) and educational (8%) services**.

We also looked at those attempting to access services at any time period prior to completing the survey. Of those attempting to access **mental health** services, 48% reported being **successful** at least once but 22% reported being **unsuccessful** at least once. And of those attempting to access **therapy** services, 57% reported being **successful** at least once but 29% reported being **unsuccessful** at least once.

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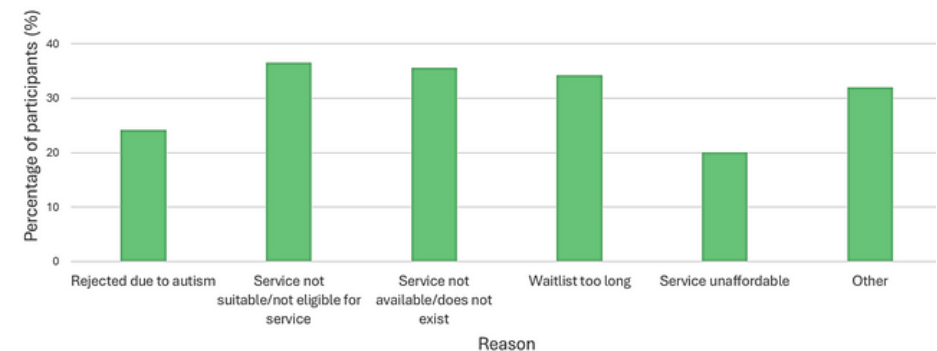
Reasons for Unsuccessful Access to Services

We looked at **barriers to accessing services overall** in the two years prior to survey completion. One of the most stated reasons for lack of access was that the service was not available or did not exist (23%), and that the service was not suitable, or people were not eligible to access it (20%). This was followed by long waiting lists (17%), unaffordability of services (12%), and being refused services due to an autism diagnosis (10%).

For mental health services, the most cited reason for not being able to access the service was being ineligible or the service being unsuitable (37%), followed by services not being available (36%) and long waiting lists (34%).

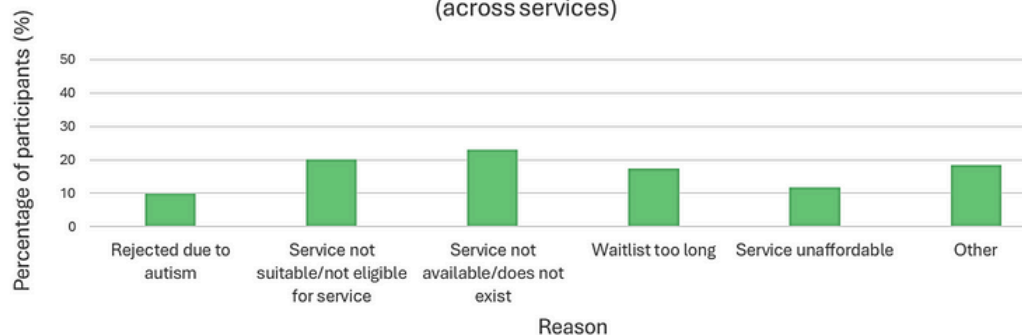
For therapy services the most reported reasons for not being able to access the service were services not being available (43%), long waiting lists (42%) followed by being ineligible for services or the service being unsuitable (33%) and unaffordability (32%).

Reasons for unsuccessful access to mental health services



Percentage of participants indicating reasons for unsuccessful access to mental health service in the two years prior to survey completion. Participants were allowed to select multiple reasons.

Reasons for unsuccessful access to services (across services)



Percentage of participants indicating reasons for unsuccessful access to services across all services in the two years prior to survey completion. For unsuccessful access to autism diagnostic services, "rejected due to autism diagnosis" was not applicable. Participants were allowed to select multiple reasons.

Reasons for unsuccessful access to therapy services



Percentage of participants indicating reasons for unsuccessful access to therapy service in the two years prior to survey completion. Participants were allowed to select multiple reasons.

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Waiting times

Data on waiting times only includes reports of access in the two years prior to completion of the survey. Most participants waited for **up to 6 months** for **most services** (e.g. therapy, housing services), but for **urgent services**, most participants waited for **less than a month**. For example, for mental health crisis support, services were received after waiting for more than a month for 39% of participants, with 30% waiting more than 6 months and 8% longer than 12 months. Although a proportion of people were able to access the service within a month, this could still be a significant wait for people experiencing a mental health crisis. For outpatient mental health services, 30% waited longer than 6 months and 15% longer than 12 months. Similarly, for educational services, 30% waited longer than 6 months and 16% longer than 12 months following referral.

Long wait times were commonly reported for an autism diagnosis, with 93% waiting for a month or more, 58% more than 6 months and 37% for 12 months or more. Note that this includes people diagnosed historically as well as in the two years prior to survey completion. **Over half (53%) of self-diagnosed** autistic participants waited a **year or longer** to access **autism diagnostic** services with no success.

Country Comparisons

Among the five most represented countries in the survey – the **UK, Spain, Poland, France** and **Germany** – all countries showed **inconsistent** access to services in the two years prior to survey completion, reporting variable levels of unsuccessful and successful access. Access to services overall was **highest** in **Germany** and **Spain** out of the five countries.

Therapy services were among the most inaccessible services in all the countries, while **mental health, educational** and **financial** services were also commonly reported as difficult to access. Participants in **Poland** reported the **most inconsistent** access to services. They recorded the highest rates of successful access across all five countries in most services but also the highest rates of unsuccessful access in most services meaning people in Poland has very variable experiences of service access. They displayed the highest rates of successful access to therapy, mental health, information/referral, educational and housing services and highest rates of unsuccessful access to diagnostic, therapy, information/referral, educational, housing and medical services.

Participants in the **UK** also reported **inconsistent** access to services, in particular reporting the highest rates of successful access to medical, social care, and helpline services. In addition, the highest rates of unsuccessful access to needs assessment, mental health and helpline services.

Participants in **Germany** reported the highest rates of access to employment and legal services. Compared to other countries Germany did not have the highest rate of unsuccessful access for any of the services.

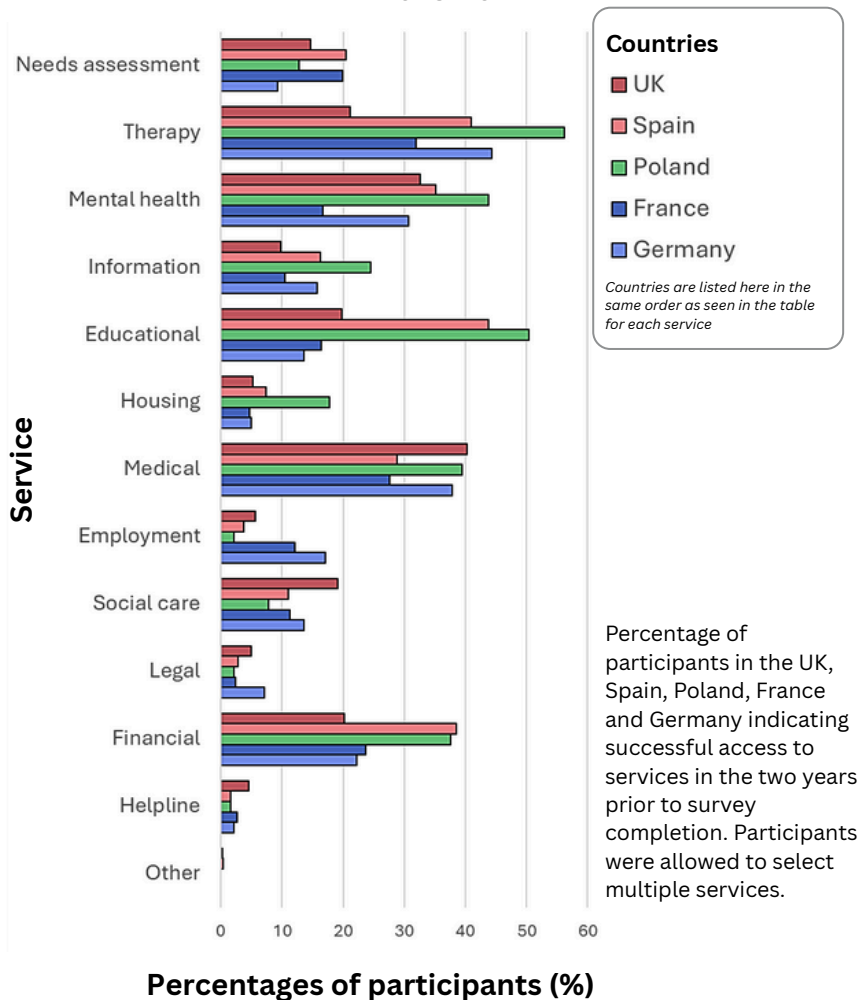
Participants in **Spain** reported the highest rate of successful access to needs assessment and financial benefits, whereas people had difficulties accessing social care services compared to other countries.

France had the lowest overall access to services compared to the other four countries. It showed the highest rate of unsuccessful access in three services – employment, legal and financial services - while not having the highest rate of successful access for any service.

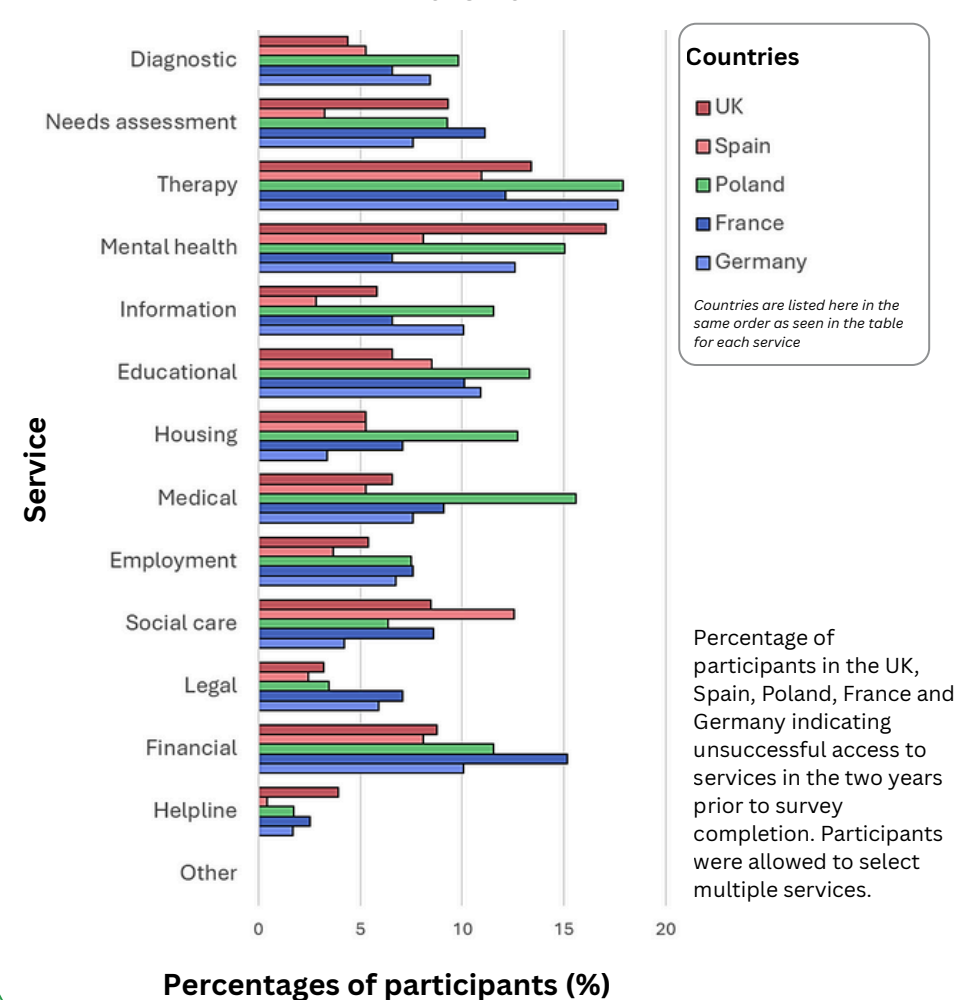
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Country Comparisons

**Successful access to services
2018-2022**



**Unsuccessful access to services
2018-2022**



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Why Are These Findings Important?

These findings are important because of the impact that challenges with service access can have on autistic people and their families. Problems and delays in accessing essential services have been shown to have serious consequences on the wellbeing of autistic people; including physical, and mental health challenges, suicidal ideation and reduced employment opportunities.

Data on how autistic people access services will be important in evaluating current policies that determine autistic people's access and experiences of services. Our findings will also serve as evidence for the integral need to design policies that more effectively improve service access among the autistic community at local, national, and international levels.

Conclusions

Autistic people experienced inconsistent access to services across Europe, and often had to wait long periods to access services and/or experienced barriers to access.

Improvements to service access for autistic people are necessary and policies mediating such changes are critical.

Highlighted Key Concerns From Autism Community Collaborators

- Autistic people need improved access to services and society.
- It is important to understand the diversity of autism in terms of the services needed – autistic people vary in their level of support needs and independence.
- Accommodations to services are often essential to allow autistic people to access them. These improve conditions for all of society but are vital for autistic people. For example, in healthcare adaptations could include improved sensory environments and flexibility in how appointments are made. People with low support needs may still need access to support services and accommodations to enable access to them.
- Autistic people have the right to reasonable adjustments to allow them to access the workplace, services, and other aspects of society.
- Services need to not just be autism aware but autism competent in their approach to working with autistic people.
- There are personal, quality of life, and economic consequences of not addressing the needs of autistic people. Improving access to mental and physical healthcare, diagnosis, employment and education can all have economic benefits as they reduce the cost of care and allow autistic people to reach their potential and contribute economically to society.
- Talking to autism communities in Europe is vital to understand the services and adjustments that are most needed.

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Appendix:

Services included in survey

Autism diagnostic services	A service providing autism assessment and diagnosis
Needs assessment	An overall assessment of support and service needs
Therapy services	Allied health services e.g. occupational therapy, speech and language therapy, behaviour support/therapy, physiotherapy, nutritionist/dietician
Mental health services	E.g. Mental health crisis support, outpatient mental health support, inpatient psychiatric treatment
Information/referral services	Services providing information on local services e.g. training, education, referral centre
Educational services	E.g. Specialist support or specialist educational setting within pre-school, nursery school, primary, secondary, tertiary settings including technical colleges and universities
Housing service/assistance	Assistance with securing and/or maintaining accommodation e.g. Semi-independent supported living, Residential supported living, subsidised housing
Medical/dental services	General Practitioner, dentist, specialist medical, emergency services
Employment services	Vocational training, recruitment agency, careers advice
Social care services	E.g. Support group, support with daily living skills, peer support, advocacy service
Legal services	Seeking legal advice or instructing a solicitor
Financial benefits/ assistance	Government assisted benefits/schemes
Helplines	Information hotlines e.g. On local autism services, health and mental health information

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Notes on analyses:

Analyses mentioned in this summary are primarily data from formally diagnosed autistic participants. Where relevant we may refer to a subsample of the original dataset of 205 self-diagnosed autistic people (for example failed attempts to access a diagnosis of autism). Percentages are given to the nearest whole number. In this report we combine findings from the self-report and parent-report versions of the survey. For successful and unsuccessful attempts to access services we present data from reports of the two years prior to survey completion and 'ever' experiences. All other findings are for the two years prior to survey completion only which included the period 2018-2022. People can report successful and unsuccessful access to the same services in the same period as the data refer to experiences of at least one successful attempt to access services and/or at least one unsuccessful attempt to access service.

The data included in this summary are not yet published at the time of writing. This summary was prepared by Rosemary Holt and Siti Nurnadhirah Binte Mohd Ikhsan, from the Autism Research Centre, University of Cambridge.

References

- This summary is based on the paper 'Access to services for autistic people across Europe' currently under review in *Molecular Autism*. Binte Mohd Ikhsan, S. N., Holt, R., Man, J., Parsons, T., Schalbroeck, R., Ruigrok, A., Baranger, A., Allison, C., Doherty, M., Van den Bosch, K., Tercon, J., Violland, P., Ghosh, A., Cusack, J., Baron-Cohen, S.
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