

# Empowering Autistic Travel

A Journey to Accessible Transport Through Participatory Research

Travel Guide for Autistic People, Families and Supporters

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# **1** INTRODUCTION

#### 1.1 What is this guide?

The National Autistic Society were funded by The Motability Foundation to address the gap in research on autistic people and travel. We involved autistic people, families and supporting professionals in a high-quality piece of user research to understand the greatest barriers and challenges autistic people experience when using transport, particularly buses and trains.

Using the data we collected through surveys and interviews, we worked with transport and accessibility experts to understand what improvements are possible, considering their industry and resource limitations. This guide summarises key actions and advice for autistic people, their families and supporters.

#### 1.2 Why is it important?

More than one in 100 people are autistic and there are at least 700,000 autistic adults and children in the UK. Autistic people face many barriers and inequalities in accessing school, work, healthcare and leisure which can be made worse by difficulties in accessing transport and making journeys. Travel, in a neurotypical world of overwhelming sensory environments and confusing social rules, can be exhausting or impossible.

"It's like a world of things out there which could really change someone's life but transport could be a barrier stopping you from being able to have all this potential. It's life changing really, having access to good, safe transport and feeling confident enough to travel on your own." - Parent of an autistic man (who is aged 25, White).

We found a distinct lack of quality, UK research on the topic. This work captured insight from the experiences of thousands of autistic people and their families, resulting in evidence-based ideas for change. You can read more about our research methods at the end of this guide. Full details of our process and findings can be found in the Research Report.

# **2** KEY FINDINGS

The most common forms of travel for autistic people, besides walking, driving and getting a lift with others, are trains (78%), buses (75%) and taxis/rideshares (56%). These are also the most uncomfortable and difficult public transport options to use, and some people





can't use them at all because they are not accessible. We chose to focus our study on these modes to ensure the greatest impact for autistic people hoping to increase their travel ability.

The greates	t barriers to autistic trave	
	Crowding	0
	Difficult sensory environments	0
	Strangers being close	0
	Delays and cancellations	0
	Anxiety of public spaces	0
æ 📖 💭	Journey planning	
	Being rushed	
	Lack of seating	0
æ	Social expectations	
	Lack of information	
æ	Not being in control	
t <del>a</del>	Feeling trapped	
v 🔂	Being misunderstood	
	Sitting still for long periods	
	Meltdowns	
	Judgement and discrimination	(
	Can't travel independently	
Key Common in taxis	Common in trains Common in buses High impact Very H	<b>1</b> igh impact





The main ways in which autistic people are **impacted** by having difficult journeys and lack of transport accessibility include:

- 1. Being anxious about travel even before their journey starts (71%)
- 2. Having to spend more time recovering/resting (68%)
- 3. Having more meltdowns or sensory overload while travelling or when reaching their destination (62%)
- 4. Being anxious about trying other forms of transport (58%)
- 5. Missing out on events or experiences they want to go to (54%)
- 6. Worrying about getting to medical appointments easily / on time (52%)
- 7. Being exhausted or overloaded when they reach their destination (51%)
- 8. Only being able to travel at quiet times, even if this doesn't suit them (49%)
- 9. Missing out on accessing hobbies and interests (46%)
- 10. Worrying about their future (44%)

They may also have:

- Loss of confidence and independence
- Hindered mental wellbeing
- High levels of anxiety, stress and exhaustion
- Emotional dysregulation
- Feelings of personal failure and frustration
- Prevention from travelling again in future

"He would come off the train, if I was picking him up, and I would be able to see in his face what it takes out of him to be in certain environments. You can see how draining the difficult journeys are compared to when he's got his headphones on, the train's on time, there's good daylight and he has his personal space." - Parent of an autistic man (who is aged 20, White).

# **3** GUIDANCE FOR AUTISTIC PEOPLE, FAMILIES AND SUPPORTERS

Most of the recommendations from our project report are for transport professionals, but some were for autistic people and their supporters. Though this guidance mostly focuses on bus and train travel, it may well be relevant to other transport modes. Overall, we found a need for:

• Support for autistic passengers





- Accessible information
- Sensory adaptations
- Autism understanding
- Reducing uncertainty

#### 3.1 Support for autistic passengers

Not all autistic people will be able to approach staff for support or use assisted travel services, even with adaptations. Sometimes the social pressures of talking to staff can be too high or they are coping with high overwhelm and cannot take on the additional task of reaching out for help (or even identifying a member of staff). Our guidance for professionals makes these difficulties clear and suggests how they can support you to get the help you need when travelling.

"I often don't have the spoons to advocate for myself in a stressful situation. It's unfair that it becomes the responsibility of the disabled person to pick up the pieces for a broken system." - Autistic woman, aged 19, White.

In addition, friends, family and carers can consider supporting autistic people to travel by:

- Maintaining contact whilst travelling, for additional reassurance and help if things do not go to plan;
- Accompanying them on practice journeys to find a comfortable routine;
- Helping to find out what support is already available from transport providers, as this can be unclear and different depending on provider and region.

It may not always be possible to keep in touch with someone while travelling, and we know that reliance on others can limit independence.

#### 3.2 Accessible information

Travel information can be difficult to process when it is not clear or accurate, compounded by busy environments with sensory distractions. Many autistic people may also be unable to approach staff, so alternative formats and easy access to information are essential to help them plan journeys and travel effectively. Having information available before travelling is also important to anticipate what may happen, help with navigation and reduce anxiety before travel.





"Often there's nobody about to ask for help. You don't know who is available to ask. You're looking for the person that's got a sign that says 'ask me a question' or something that identifies them as the person who you can trust. We need clear signage, and an app that gives you information without having to speak to a person would be even better." -Parent of an autistic man (who is aged 25, White).

All of our suggestions to address this gap in clear, accurate, accessible information are directed to the transport industry.

#### 3.3 Sensory adaptations

Journeys and travel plans are made much more difficult due to the sensory differences. For anyone that travels, it is mostly unavoidable to enter situations that are loud, crowded, bright, cluttered, busy and have unique smells and differing levels of cleanliness. Sensory stress reduces the ability of autistic passengers to process information such as announcements, and can trigger meltdowns or make them feel very unsafe.

"From sensory point of view, there are so many sounds, the smells, the proximity of people. People aren't following rules, they're vaping on buses. Others have got their music on and they're being so loud and inconsiderate." - Autistic woman, aged 36, Black African and White.

With some environmental adjustments it could be possible to make these intense sensory environments more accessible to autistic people. As well as changes being made by service providers, autistic people and their supporters can:

- Seek opportunities to offer consultation with transport professionals on how they can redesign services and waiting spaces
- Use headphones and noise cancelling items
- Bring regulatory and comfort items such as fidget toys, puzzles and safe foods
- Distract themselves by engaging in a pleasurable activity such as music or reading

#### 3.4 Autism understanding

Autistic participants felt that there is a lack of public empathy which comes from not understanding the challenges that autistic people face. Some have even faced abuse and





explicit discrimination when using transport which has a lasting impact on their confidence to travel alone again.

"If you've had a long day, sometimes that [stimming] helps to do, but then you can't because, you're in public and someone might, you know, start yelling at you or saying something or calling you slurs." - Autistic woman, aged 18, Bangladeshi.

We have recommended public campaigns to help other passengers understand autism and the difficulties autistic people may face with travel, to improve acceptance and expectations. Everyone can help to inform the public by sharing research, guidance and campaigns that they come across.

#### 3.5 Reducing uncertainty

Much of what is hard about travel is that a lot of your journey is out of your control. Autistic people told us that they need timely access to up-to-date, accurate information to help them know what to expect. Helping to reduce uncertainty about the journey is important to help autistic people feel confident about travel.

"When things go wrong or things change, you've been travelling for a very long time and then something happens unexpectedly and you've got less bandwidth then to be able to deal with it like you normally would." - Autistic woman, aged 36, Black African and White.

While there is nothing that can be done to prevent incidents that cause change, there were some good ideas from autistic people and their families to help reduce uncertainty and increase predictability. You can try to:

- Access live trackers to know exactly what is happening in real time
- Emotionally prepare for a journey by actively taking time to relax beforehand
- Make time to reflect and recover from the journey afterwards
- Practice journeys to increase familiarity and reduced unpredictability
- Prepare by learning routes and understanding journey timings to increase confidence
- Use quieter travel times where possible
- Choose modes the provide the greatest control
- Plan strategies to manage not being in control





- Plan any transition points, if there is a need to switch between different services and modes
- Make an emergency plan covering what they could do if something went wrong during the journey
- Keep things the same where possible by keeping to a preferred mode, sitting in the same seat when available and taking the same route to the station

# **4** ACCREDITED SERVICES

#### 4.1 Autism friendly support

There is great variety in the accessibility of services and support provided. Autistic people can also have varying needs and personal preferences, for example some told us they prefer big, well-staffed stations whilst others favour quiet, rural stations. For this reason, we can't highlight particular services or spaces to recommend. However, our accreditation scheme, the Autism Friendly Award, does help in recognising services and spaces who have carefully considered their provision of support for autistic people.

#### 4.2 What is the award?

The Autism Friendly Award is aimed at businesses, attractions and venues that an autistic person may visit. It is about the overall accessibility of the autistic visitor experience. This accreditation confirms that the organisations meet certain standards to provide an autism-friendly environment and inclusive customer service. For example, the award ensures:

- Employees understand how to effectively communicate with autistic people
- Spaces are made more accessible and less overwhelming for autistic people
- Information is provided about the venue to help autistic people plan their visit
- Local communities are more inclusive

There is no expiry, though it is recommended that organisations are reassessed every 3 years to ensure that the customer experience is still positive and possibly even improved. You can find out more about the award here: <a href="https://www.autism.org.uk/what-we-do/autism-know-how/autism-accreditation/autism-friendly-award">https://www.autism.org.uk/what-we-do/autism-know-how/autism-accreditation/autism-friendly-award</a>.

#### 4.3 List of services

Below is a list of services and stations have been awarded an Autism Friendly Award by the National Autistic Society, including the year they were accredited.





- East Midlands Railway Nottingham to Skegness line only (2023)
- Great Western Railway whole network (2025)
- Lancashire Community Rail (2023)
- Lothian Buses (2024)
- Nexus North East (2023)
- Red Funnel Ferries (2023)
- Waterloo station (2024)
- Waverley Hoppa Service (2023)

#### 4.4 What to look out for

You can use our Autism services directory to search for autism-related organisations including but not limited to those who have received the Autism Friendly Award: <u>https://www.autism.org.uk/autism-services-directory</u>. Look out for the Autism Friendly Award logo from services near you, as more organisations are accredited every year.



### **5** AUDIENCE RECOMMENDATIONS

Through our research we asked autistic people and those who support them to share their recommendations for travel support resources. These recommendations are shared strictly without endorsement by the National Autistic Society. The following resources have not been tested by the project team and are not an extensive list of the support options available to you, but are those discussed by our research participants.

#### 5.1 Disclosure tools

Cards and lanyards to let staff or other passengers know that you may need additional support or patience on your journey.

- Orange wallet / card (free to access, recognised across Wales) <u>https://tfw.wales/info-for/passengers/accessible-travel/initiatives/orange-wallet-scheme</u>
- Travel support card (template to complete at home, provided by TFL) <u>https://content.tfl.gov.uk/travel-support-card-printable.pdf</u>





- Priority seat card (evidence required for approval, for use on Southern, Thameslink, Great Northern or Gatwick Express services) <u>https://www.greatnorthernrail.com/accessibility/priority-seat-card</u>
- Access Card (to communicate access requirements at venues and online) <u>https://www.accesscard.online/</u>
- National Disability Card https://www.disabilityid.co.uk/
- Sunflower lanyard (to signal hidden disability) <u>https://hdsunflower.com/uk/shop/sunflower-wearer.html</u>
- Sunflower Extra card (NFC card which displays personalised information when tapped a mobile phone) <u>https://hdsunflower.com/uk/insights/post/extra-guide</u>
- Helping Hand card (to signal additional needs to bus providers, such as asking for patience or to wait until seated to drive on) <u>https://www.morebus.co.uk/helping-hand</u>
- National Autistic Society 'I am autistic' card (for download and printing)
  <u>https://www.autism.org.uk/advice-and-guidance/resources/downloads/i-am-autistic</u>
- JAM 'Just a Minute' Card (to indicate you need extra time) <u>https://www.jamcard.org/</u>
- 'Please offer me a seat' card and badge (for use on TFL services) <u>https://tfl.gov.uk/transport-accessibility/please-offer-me-a-seat</u>

#### 5.2 Discounted travel passes

Depending on your area and circumstances, you may also be able to get financial support with transport from your Local Authority.

- Disabled Persons Railcard (National Rail) <u>https://www.disabledpersons-railcard.co.uk/</u>
- Disabled Coachcard (National Express)
  <u>https://www.nationalexpress.com/en/offers/coachcards/disabled</u>
- Disabled Person's Freedom Pass (London residents, may be awarded discretionally for London transport only) <u>https://www.londoncouncils.gov.uk/services/freedom-pass</u>

#### 5.3 Travel advice articles

Some transport services also publish their own assistance guides and virtual station tours on their websites.

- Negative attitudes on public transport (Scope) <u>https://www.scope.org.uk/advice-and-</u> <u>support/negative-attitudes-from-other-passengers-on-public-transport</u>
- Asking for a seat on public transport (Scope) <u>https://www.scope.org.uk/advice-and-support/asking-for-a-seat-public-transport</u>
- Finding accessible transport and planning your journey (Scope) <u>https://www.scope.org.uk/advice-and-support/finding-accessible-transport</u>





- International travel (Scope) <u>https://www.scope.org.uk/advice-and-support/travel-and-transport/holidays-and-travel-abroad</u>
- HUBS Mobility Advice Service <u>https://www.hubsmobilityadvice.com/</u>

#### 5.4 Information and planning apps

Many transport providers also have their own apps and websites which may contain the most reliable and up-to-date information in fast-changing scenarios. The following apps have been recommended to find information across services or more accessible formats.

- AccessAble (station descriptions and facilities)
- Apple Maps (journey planning)
- Arriva (journey planning)
- Aubin (designed for autistic passengers)
- Bee Network (Greater Manchester only)
- Brain In Hand (coping at difficult times)
- Bustimes.org
- CityMapper (journey planning in limited UK cities)
- Footpath Route Planner (planning routes to transport with audio and visual navigation cues)
- Google Maps (journey planning, visualising locations and commute option)
- Hugo (buses)
- JourneyCheck (trains including disruption information)
- London & UK Live Bus Countdown
- Moovit (bus)
- MyTrip (buses)
- National express (coaches)
- National rail (trains including station maps and distruption information)
- Omio (trains)
- Passenger Assistance (trains)
- Platform (trains)
- PokemonGo (journey tracking as stations may be named stops within the game)
- Railboard (trains)
- realtimetrains.co.uk (detailed train information and platforms)
- Rome2Rio (journey planning)
- Scotrail
- Seat61.com (detailed anecdotal guidance and visualising carriages for UK/EU trains)
- Seatfrog (bidding for first class upgrades)



- Service provider apps and accessibility webpages (e.g. Transpennine Express, First Bus, EMR, LNER)
- TFL Go (London tubes, buses and trains)
- TFL Journey Planner (London only)
- toiletmap.org.uk (map of public toilets)
- Trainline (trains)
- Trainpal
- Translink Journey Planner (buses and trains in NI)
- Traveline Cymru (journey planning for Wales)
- Traveline Scotland (journey planning including trams and ferries)
- Uber (taxis including location tracking)
- Wanderlog (planning multiple journeys in a trip)
- Waze (journey planning)

#### 5.5 Campaigns

- It's everyone's journey: Championing equal access on public transport (Department for Transport, 2024) <u>https://everyonesjourney.campaign.gov.uk/</u>
- For All General Election 2024: Why accessible transport for disabled people must be a priority for the new Government (Transport For All, 2024) <u>https://www.transportforall.org.uk/take-action/campaign/general-election-2024/</u>

#### 5.6 Legal advice

- Right to Ride guide (Scope) https://www.scope.org.uk/right-to-ride
- Rights of disabled passengers on transport (Department for Transport)
  <u>https://www.gov.uk/guidance/rights-of-disabled-passengers-on-transport</u>
- Complaints about public transport (for England and Wales)
  <u>https://www.scope.org.uk/advice-and-support/complain-about-public-transport</u>
- Rail Ombudsman <a href="https://www.railombudsman.org/about-us/">https://www.railombudsman.org/about-us/</a>

#### 5.7 Forums and working groups

Some providers and campaign groups consult with autistic people to identify accessibility problems and workshop options for change.

• Transport for All (disabled-led campaign group) https://www.transportforall.org.uk/



- Learning Disability Transport Forum (with Transport for London, for learning disabled and autistic people) <u>https://www.peoplefirstltd.com/articles/transport-for-londonexpert-by-experience-network</u>
- Transport Focus (independent watchdog, anyone may apply to join the panel) <u>https://www.transportfocus.org.uk/insight/transport-user-panel/</u>
- Built Environment Accessibility Panel (with Network Rail)
  <u>https://www.networkrail.co.uk/who-we-are/diversity-and-inclusion/access-and-inclusion/inclusive-design/built-environment-accessibility-panel/</u>
- Disability Unit Regional Stakeholder Network (to raise regional issues the government should address for disabled people, anyone may apply to join the network) <u>https://www.gov.uk/government/groups/disability-unit-regional-stakeholder-network</u>
- Access Advisory Panel (with Great Northern Rail) <u>https://www.greatnorthernrail.com/help-and-support/contact-us/access-advisory-panel</u>

#### 5.8 Research articles

Publicly-available summaries of research on accessibility for autistic or disabled people.

- Travel Fair report (Scope, 2019) <u>https://www.scope.org.uk/campaigns/travel-fair/travel-fair-report-summary</u>
- Transport Focus data hub (panel surveys from the independent watchdog) <u>https://transportfocusdatahub.org.uk/</u>
- Transport Focus research reports <u>https://www.transportfocus.org.uk/publications/</u>
- National Centre for Accessible Transport (evidence centre and consortium influencing the transport sector to ensure accessibility for disabled people) <u>https://www.ncat.uk/about-us/</u>
- Making public transport accessible for neurodivergent people (Autistica, 2024-25) <u>https://www.autistica.org.uk/our-research/research-projects/accessible-public-transport</u>
- Disabilities, travel and mental health (Mental Health Innovations, 2024) <u>https://mentalhealthinnovations.org/news-and-information/latest-news/disabilities-</u> <u>travel-and-mental-health/</u>

#### 5.9 Other support

 Shout (text 'TRAVEL' to 85258 for free 24/7 mental health support by text message – before, during or after your journey) <u>https://giveusashout.org/latest/stressed-or-</u> worried-about-travelling-were-here-for-you/





 Mencap Travel Training (for people with a learning disability) <u>https://www.mencap.org.uk/advice-and-support/travel/local-transport-initiatives</u>

# **6** OUR METHODS

We used a mixed methods approach, collecting quantitative and qualitative data from a broad range of research activities:

- Rapid review of research, professional resources and blogs from autistic people
- Scoping survey of 560 respondents, to find out which transport types are most commonly used and difficult to use for autistic people, to shape our specific topic
- **Co-design group** of 8 autistic members who represented the diversity of the autistic population and guided the project through discussion sessions and review work
- Insight survey of 3,375 respondents, to better understand the greatest and most impactful challenges on trains, buses and taxis; as well as user ideas for solutions
- User interviews with 16 autistic people and 4 parents/carer to get a deeper understanding of people's difficulties with travel and ideas for change
- Focus groups with 10 transport professionals, researchers and accessibility experts to discuss autistic travel challenges and understand their limitations for making change
- Solution building workshops with 19 professionals to discuss refined user ideas and assess them for suitability, feasibility and acceptability

It was important that this project was autistic-led. Along with our two autistic project leads, we recruited an autistic co-design group to work with us throughout, including consultation on planning insight gathering, interpreting findings and refining priorities and outputs.

At every stage of the research we sought inclusion from typically underrepresented autistic people: those with significant communication differences, co-occurring conditions, and people of the global majority. We also ensured that samples had a diverse mix of rurality, ethnicities, age, genders, regions, verbal ability, driving ability and complexity of need.

A majority of our data is from autistic people who are diagnosed or self-identifying. On the advice of the co-design group, we also included relative, friends, carers and supporting professionals who gave second-hand accounts of a particular autistic person they are close to. In the later stages of the project, we also sought the transport industry perspective on solutions, to ensure our recommendations work in practice.





This was a thorough and robust piece of participatory research, being truly autistic-led in its delivery and successfully addressing the evidence gap on autism and transport. You can read the full methodology in the Research Report.

## **7** RESOURCES



The full Research Report is on our website (with more Empowering Autistic Travel resources added Summer 2025) <u>www.autism.org.uk</u>



Email address for enquiries: research@nas.org.uk





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