

Empowering Autistic Travel

A Journey to Accessible Transport Through Participatory Research

Accessibility Guide for Transport Professionals & Industry Leads

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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
- Identify evidence-based and feasible solutions to make transport more accessible to autistic people
- Establish which changes and interventions autistic people would most like to see and how these fit in with industry capabilities

We captured the views and experiences of thousands of people through surveys, interviews and workshops. Using this data, we worked with transport and accessibility experts to understand what improvements are possible, considering their industry and resource limitations.

This guide summarises key findings, spotlights some autistic passengers' travel stories and outlines project recommendations for the transport industry. We have produced a separate guide for autistic people and their supporters, outlining the steps they can take to improve their journey experience. You can find the other guide along with our full project report, a brief overview, a short film and other resources on the project page linked at the end of this guide.

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 using transport and making journeys.

"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

In a neurotypical world of overwhelming sensory environments and confusing social rules, travel can be exhausting or impossible for autistic people. We found a distinct lack of quality, UK-based research this topic, and set out to address the evidence gap. We

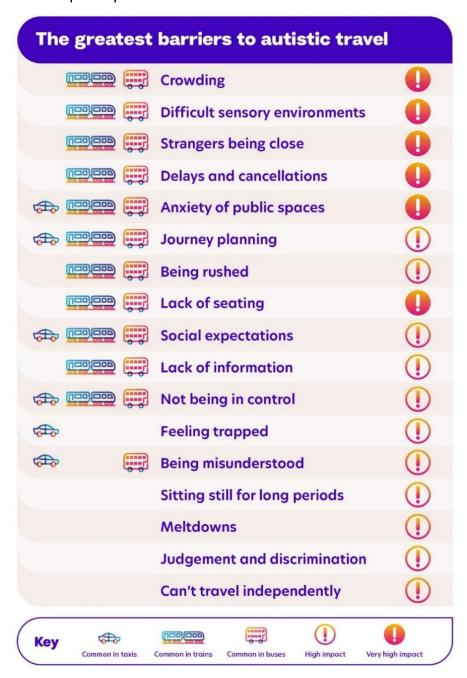




produced a thorough and robust piece of participatory research which was autistic-led.

2 KEY FINDINGS

An initial survey told us that 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 find them too inaccessible to use at all. We therefore chose to focus our study on these modes, though much of the findings can be applied to wider transport options.









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
- High levels of anxiety, stress and exhaustion
- Feelings of personal failure and frustration
- Prevention from travelling again in future

"He would come off the train and I could see in his face what it takes out of him. 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

3 ACCESSIBILITY RECOMMENDATIONS

Many of the recommendations from our project report are for transport professionals and industry leads, and can be actioned across the short and long term.

Overall, we found a need for:

- Support for autistic passengers
- Accessible information
- Sensory adaptations
- Autism understanding
- Reducing uncertainty





You play a crucial role in helping to make transport accessible for autistic people. Whatever stage you're at in developing systems to support this, please consider how to incorporate these recommendations which are the result of thorough user-led research.

3.1 Support for autistic passengers

Assisted travel, including support both at stations and on board, can sometimes help autistic people to navigate the difficult environments and know what to do when things change. Often such services need to be booked in advance, and sometimes autistic people are refused assistance because providers don't understand why they'd need it. To ensure good support for autistic passengers, assisted travel must be available to those who need it, easy to arrange, flexible and reliable. Providers could partner with a recognised autism support scheme or adapt their disability assistance to ensure inclusion of autistic passengers.

Autistic people often cope with high levels of overwhelm during travel, which can make it difficult to identify which staff could be approached for help. They need dedicated transport professionals who are trained to understand autism and offer patient, sympathetic support. It's important that trained staff and help points are clearly identifiable and can offer support such as:

- Sympathy, kindness and reassurance when they are in distress
- Patience if they need time to process and respond
- Help with making decisions, particularly when there are unexpected changes
- A quiet, uncrowded space to recover from shutdown, meltdown, overload or panic
- Being understanding of people who cannot communicate verbally when in distress, or at all
- Assistance and benefit of the doubt if they have an incorrect ticket type
- Offering communication cards (discreet and nonverbal) and sensory regulation tools (e.g. ear defenders, capped hats and fans)

"Often there's nobody about and you don't know who is available to ask for help.

You're looking for a sign that says 'ask me a question' or something that identifies them as the person who you can trust. An app that gives you information without having to speak to a person would be even better." - Parent of an autistic man

Having dedicated staff to support autistic passengers can reduce anxiety, discrimination and stigma, while also improving their independence and confidence. Supportive interactions with staff help connect autistic people to the assistance they need, making them more likely to complete their journey.





Not all autistic people will be able to talk to staff or use assisted travel services, even with adaptations. It's important that transport websites include clear information on the support available to autistic passengers and how they can access it.

Providers should also consider pursuing autism friendly accreditation to learn more, promoting existing support and working with travel trainers. For autistic people who need the support of a carer to cope with travel, discounted rates on accompanying carer tickets should also be offered where possible.

3.2 Accessible information

It can be difficult for autistic people to process information in busy, overwhelming environments. Information should be clear, accurate, easy to find and offered in a range of formats, including easy-read text, so that everyone has access. It is especially important for information about services and any changes to be available in advance, as it may help autistic people to help plan their journey, anticipate what may happen and reduce anxiety before travel.

Some of the other types of information autistic people would benefit from include:

- Static electronic screens to deliver travel announcements
- Live service capacity indicators through official sources
- Signage for queues, where carriage doors will open and where to wait for quiet carriages
- Clearer signposting at stations, particularly towards exits and indicators to the closest exist when the priority is exiting quickly
- Floor markings and colour coding to direct passengers to sensory safe spaces
- Explanations for delays and cancellations where possible
- Visual instructions on how to use ticket machines and barriers
- Detailed instructions on ticket-buying processes and options
- Improved clarity of maps and timetables
- Increasing the use of virtual walk-throughs to see the environment in advance
- Contact details for station and travel enquiries being clearly displayed for further clarification

Where possible, information across multiple services should be combined into a single official source to improve access. While we understand reliability issues with third-party travel apps, the volume of options and formats can make finding timely information even more difficult. Digital services are not always easy to navigate and vary in how comprehensive they are.





Autistic people would welcome apps which are tailored for those who communicate differently, provide advanced and live information, allow booking for all transport types and give guidance which is accurate, reliable and consistent.

3.3 Sensory adaptations

Travel can be made much more difficult due to the sensory differences many autistic people have. For anyone who travels, it is mostly unavoidable to be in situations which are loud, crowded, bright, with unique smells and differing levels of sanitation. These environmental elements can cause sensory stress for autistic passengers, reducing their ability to process information such as announcements, making them feel unsafe or in pain, and potentially triggering meltdowns.

"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

With some environmental adjustments, it could be possible to make these intense sensory environments more accessible to autistic people. It would help if stations provided adjustments such as:

- Quiet safe spaces which are low-arousal (e.g., dark, clean and cool) and include sensory regulation tools
- Clearly displayed information about the purpose and proper use of these spaces
- Pre-bookable quiet carriages, featuring the same low-arousal adaptations as well as having softer textures, single seating or dividers between seats and lacking busy advertisements and visual patterns
- The ability to anonymously remotely report problems with safe space environments
- Increasing the use of electric vehicles for quiet travel
- Allowing for breaks in the journey on the same ticket

While the implementation of autism friendly spaces can be difficult for providers due to logistical and financial barriers, there are often workarounds or small changes towards these goals which would make a great difference. For instance, in the absence of a dedicated waiting room, first-class lounges could be partially repurposed to improve accessibility.

Before making changes to station and carriage design, service providers should always endeavour to consult with autistic people to determine the impact on them and what could best address their needs. Where there are barriers, consider 'next-best' alternatives and clearly communicate to customers the limitations which prevent you from offering fully





inclusive service, so that they know what to expect during travel and can recognise how their needs have been understood.

3.4 Autism understanding

Autistic people recognise that the public sometimes lack empathy and don't understand their challenges, including during travel, which can prevent them from accessing support and expose them to the judgemental attitudes of fellow passengers and staff. Some people 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 you can't, because you're in public and someone might start yelling at you or calling you slurs." - Autistic woman

It is important that transport providers do their part to keep autistic passengers safe during travel by helping to spread accurate information about autism, including sharing research, guidance and campaigns with their passengers and networks. In particular, it would help if there was better public understanding of meltdowns and self-soothing behaviours, what other passengers can do to support them, and common communication differences (e.g., being uncomfortable with social contact, increased processing time and being nonspeaking).

Educating the public can go a long way towards increased recognition of autistic people, more empathy and ultimately more acceptance of the different ways people show up on transport. Better awareness could make autistic people more able to ask for support when they need it, reduce misunderstandings, protect them from discrimination and reduce the many stressors they encounter during travel.

Staff should also know to offer support or ask what someone needs even if they're not sure if they're autistic. There is no one way autistic people look; they can be all ages, genders and ethnicities and may keep their distress inside and appear to be coping fine.

Care should also be taken to ensure that all staff receive proper autism training and work with autistic consultants to design and evaluate any new initiatives in the service. Improved understanding of autism from staff helps autistic people have the confidence to travel and ask for support when they need it. Services can also consider:

- Allocating a named autism champion in their staff team to advocate for autistic users
- Accessing an autism friendly accreditation scheme or award





- Inviting autistic passengers on ride-along journeys to better understand their experiences
- Promoting and share existing access schemes more widely
- Participating in industry forums and working groups to share knowledge and overcome barriers to changing the service
- Raising awareness of hidden disabilities and the support offered

3.5 Reducing uncertainty

One of the hard things about travel for autistic people is that the journey is often out of the passenger's control. Managing uncertainty about the journey is key to ensuring that autistic people feel confident and able to travel. Autistic people need timely access to upto-date, accurate information to help them know what to expect.

"When you've been travelling for a very long time and then something happens unexpectedly, you've got less bandwidth to deal with it like you normally would."
Autistic woman

Whilst there is nothing that can be done to prevent incidents that cause change, there's a lot that transport providers can do to prepare passengers for what could happen on the journey, such as:

- Giving advance notice of changes to routes and timetables, even if they are regular seasonal shifts
- Quickly communicating information on delays and replacement travel in accessible formats
- Developing travel planning resources such as checklists and visual stories
- Implementing and supporting travel training schemes to plan and test out new journeys
- Improving the consistency between vehicles across the industry
- Publishing descriptions and pictures of carriages to help people know what to expect
- Simplifying ticket types and offering online and staffed purchasing options





4 CASE STUDIES

Elevating autistic voices has been an important element of our approach throughout this project. In our case study series, we share real stories of difficult travel experiences, written by autistic people who assisted our research. Here we present excerpts of their stories to bring the issues highlighted to life, and help demonstrate the need for industry change. You can find the full series of stories on the project page linked at the end of this guide.

4.1 Harper's story: "All I could think about was being trapped"

Harper, 39, lives in London and works fully remotely. This means that she doesn't use public transport on a daily basis, though she does rely on it to attend a weekly course, and for grocery shopping. She tends to walk or cycle where she can. As long as the weather is good and the journey is under an hour by foot or bike, Harper prefers to avoid public transport as other passengers can be loud:

"The main barrier for me is the sensory overload, especially the noise. On most of the buses I take there's someone on the phone speaking very loudly or who even has the speaker on. Sometimes they're watching something or listening to music aloud. Many times, it's even several people and the noise just gets very overwhelming."

The noise and disruption from other passengers can be made worse by overcrowded services and waiting areas. Having others very close makes Harper feel uncomfortable and overwhelmed:

"Public transport can be very crowded, with people standing or sitting very close next to me. I get especially anxious when someone suddenly touches me, no matter if it's accidentally, trying to get their phone out of their pocket, or squeezing past me to get to the doors.

Sometimes people stand so close that I can feel their breath on my neck or body, which has led to me leaving the tube and waiting for another, less crowded service as the sensation of this just got too overwhelming."

Harper describes a recent incident on her regular bus which was particularly full, leading her to feel trapped and overwhelmed:

"I couldn't get a seat which generally isn't important to me as long as I find a little corner for myself. I ended up standing next to the back door, with my earphones in to listen to some music, but even at high volume my music can't block the noises





out. There are a lot of different smells (perfume, sweat, food smells probably from takeaway) and I start to feel a bit nauseous.

Then, the bus enters the tunnel and the bright light switches on. I was pressed against the door of the bus, as far from other people as possible, but occasionally people touched against my arms and shoulders. I just looked straight down as the light was too bright. My body was all tense and I just froze. I had to actively control my breathing as it felt like someone was holding me from behind. I was about to cry, actively holding back tears and closing my eyes. I realized later that I'd been biting the insides of my cheek.

All I could think about was being trapped like this until the bus left the tunnel. It felt like an eternity until the lights were switched off and we were out of the tunnel. I got off at the next stop and stood there for a little while, crying. I walked the rest of the way instead of waiting for another bus."

Harper's experience had a strong and painful effect, and she did not even reach her destination. Many of the autistic people we surveyed described similar experiences of needing to abandon their journey and, like Harper, having to change or cease their plans for the rest of the day. The sense of dread stayed with her throughout the day.

Some of the things which make travel more accessible for Harper include spacious surroundings and clear information, which should be incorporated into service design. Harper explains how these elements make all the difference, describing a route which she finds more comfortable:

"I take the Elizabeth line from time to time and find the travel experience quite pleasant. The platforms are bigger than on the other tube lines, so there is generally less crowding. The trains are fairly big as well. Whenever I've used the line I've had enough space on the platform and I've never experienced any crowding on the train itself.

I also like that they have aircon, which makes the travel much more pleasant as it's not boiling hot, and it also seems to help with overwhelming smells. I still wear my earphones to help with noise overload and the light is sometimes too bright, but having less sensory stimuli to deal with certainly helps.

I also find the displays in the trains very clear and helpful – e.g. the screens showing the next station. On other lines, the screens are not always working and it can get a bit confusing without them."





4.2 Steph's story: "I was left stranded and hysterical"

Steph, 58, lives in a small town in the West Midlands. She prioritises running costs for her car, because if she relied in public transport then she'd rarely go anywhere. Steph carefully planned a recent bus trip with her grandchild which went surprisingly well, though she felt a sense of terror ahead of the short journey. Some of the main things which put her off public transport are unreliable services and the unpredictability of other passengers:

"I have no control over the people sitting next to me, people sitting in a seat I've previously booked on the train, smelly people, people affected by various substances or mental health. I just don't feel safe and I've heard horror stories of train conductors not stepping in when awful things have happened to train passengers.

I've also arrived at train stations to find that my train has been delayed or cancelled and I have no idea what I'm supposed to do then. I've felt very lost and frightened."

Unfortunately, many of the autistic people we surveyed disclosed that they feel unsafe in public spaces, particularly public transport. Steph finds it especially difficult when her journey unexpectedly takes her to unfamiliar places:

"I was on a coach that I boarded in Stoke for a return journey to Bristol. I was turfed out in Birmingham on the way back, on a very cold dark evening, and told that that's where the service terminated. I was left stranded and quite hysterical until a kind person put me on a train home. I've been able to revisit the trauma of being abandoned by the coach company. Instead of feeling sick, I now feel justly angry that I was treated so appallingly.

Another time, I'd had an accident involving my sight which left me very disorientated, and I ended up on the wrong bus. After an hour I was able to get off at the depot and once again I was in a huge panic."

Many of the autistic people we spoke to also described other passengers' reactions to their distress as one of the most difficult aspects of travel. Sometimes people can be judgemental and, as Steph describes, struggling like this in public can cause a sense of shame:

"I think people are used to young children having meltdowns but when they see it happening to a 50-year-old woman it's a very different story. When you're older, you feel that you should be able to cope and deal with things, but it's not always the case. I was very late diagnosed and I feel that I'm still coming to terms with it. I hate the limitations I have."





5 RESOURCES



The full research report (including full methodology) and case studies along with other resources are on our project page:

www.autism.org.uk/what-we-do/who-weare/research/empowering-autistic-travel



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

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