

Empowering Autistic Travel

A Journey to Accessible Transport Through Participatory Research

Research Overview

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1 Introduction and Context

The National Autistic Society were funded by the Motability Foundation's 2024 user research grant to address the gap in research on autistic people and travel. The project was a high-quality piece of user research, led by autistic people, that:

- addressed the evidence gap on autism and transport;
- provided vital insight into autistic people's experiences of transport and travel;
- proposed solutions and recommendations for change.

This Research Overview summarises the research method, findings and recommendations of the project. (For full findings and recommendations please see the main Research Report.)

1.1 What is autism?



Autism influences how people experience and interact with the world. It is a lifelong neurodivergence and disability. Autistic people are different from each other, but for a diagnosis they must share differences from non-autistic people in how they think, feel and communicate.

Autistic people may feel things and react to them differently to non-autistic people. They may find socialising confusing or tiring, and may become overwhelmed in loud or busy places. They may have intense interests, prefer order and routine, and use repeated movements or actions to calm themselves or express joy. Many autistic people mask their discomfort to fit in, which can lead to mental illness.

More than one in 100 people are autistic and there are at least 700,000 autistic adults and children in the UK. We know that autistic people face a myriad of barriers and inequalities in accessing school, work, healthcare and leisure. These can be exacerbated by travel difficulties, including difficulties in accessing transport and making journeys. Getting from A to B for an autistic person involves navigating a neurotypical world of overwhelming sensory environments and confusing social rules, which all takes a heavy toll.







We completed a review of published academic research, professional guidance, and lived experience accounts (blogs and vlogs), to capture current information on the topic of autism and transport.



The rapid review demonstrated a distinct lack of UK-based, quality research on this topic. What we found mostly focussed on children, and use of technology in transport. Sample sizes were small and findings not generalisable.

Professional guidance, and vlogs/blogs from autistic people were also limited, with autistic people demonstrating some common challenges to travel, as well as strategies to reduce barriers.

Suggested challenges to travel included (Rezae et. al., 2021; McMeekin et. al., 2020; Lowery, 2017; Jones, 2017; Aoife, 2018):

- anxiety about the journey;
- crowds and lack of space;
- unexpected events (e.g. cancelled transport or diversions);
- sensory overload;
- difficulty with trip planning;
- social anxiety, and communication differences impacting ability to access support.

Suggested strategies to reduce barriers included (Dirix et. al.2023; Amatina, 2023; Lowery, 2020; Jones, 2017; Gandecha 2018; Aoife, 2018).

- providing training for staff;
- ensuring accurate and accessible information;
- travelling during off-peak, quieter periods;
- bringing sensory tools;
- travelling with someone.

The review demonstrated a clear need to expand on the topic with a high-quality, participatory approach.





2 Methodology

2.1 Participation



It was important that this project was led by autistic people. Along with our 2 autistic project leads, we recruited an autistic led co-design group (CDG) to work with us throughout. The 8 CDG members were consulted on tasks such as planning our insight gathering, interpreting findings, and refining priorities and outputs.

We screened expressions of interest considering demographic diversity – wanting the group to be reflective of the diverse autistic population. We then captured experiences of a large number of autistic participants through surveys, and more in-depth views through interviews. We particularly sought inclusion from typically underrepresented autistic people – those with significant communication differences, co-occurring conditions, and people of the global majority. We also consulted parents/carers, and transport professionals. This resulted in a rich combination of qualitative and quantitative data

We used an ongoing recruitment form to invite participants to the various research activities, shared via social media, website and email channels throughout the project. We took a more targeted approach to recruit transport professionals, pro-actively emailing different network providers.

We ensured compliance with professional code of ethics and ethical guidelines, specifically for vulnerable adults, and took steps to support participants in their engagement.

2.2 Research Activities

Activity

- **1.** Rapid review review of current research, professional resources and vlogs/blogs of lived experiences
- 2. Scoping survey a small survey to capture issues to shape research aims
- **3. Co-Design Group (CDG)** an autistic co-design group to meet regularly to make study design decisions
- **4. Insight survey** a large scale survey to collect quantitative and qualitative data about autistic travel experiences
- **5.** Travel user interviews semi-structured interviews with autistic people and parents/carers representing autistic people







- **6.** Transport professional focus groups to discuss the professional perspective on autistic travel challenges, including rail providers, researchers and accessibility leads
- **7. Solution testing workshops** to discuss the 'user ideas' with professionals and assess them for suitability, feasibility and acceptability
- **8.** Output survey to collect data about which formats and channels we should use to share findings and further resources

2.3 Data Samples



The scoping survey was completed by 466 autistic people and 94 relatives, friends, carers or supporting professionals. Participants were diverse in age, gender, geographical location, ethnicities and support needs, however the majority were from the South East, female, and white.

We changed our recruitment approaches for the main insight survey, to ensure a more representative sample. The insight survey had a diverse sample of 3375 responses:

- 80% of respondents were autistic people, and the remainder relatives, carers, friends or supporting professionals answering on behalf of an autistic person.
- Over 9 in 10 autistic people we sampled reported that they have co-occurring conditions (including health conditions which can make travel even more challenging)

Our interview selection ensured a mix of rurality, ethnicities, age, genders, regions and autistic people who indicated intermittent speaking ability or use of carers. The interviews were held online, transcribed and anonymised. Data was then thematically analysed, meaning interview transcripts and notes were dissected into key points, categorised, and common themes across the discussions identified (Attride-Stirling, 2001).

For professional perspectives, we engaged with council transport planners; travel trainers; researchers of transport and accessibility; accessibility, diversity and inclusion officers in bus and rail; and service level staff. We gathered 10 attendees across 2 focus groups and a further 19 in various solution building workshops, including varying levels of seniority and autistic members of staff. At the workshops we presented insights from the research and proposed the suggested solutions. These solutions were grouped into themes, and each discussed, in relation to their Suitability, Feasibility and Acceptability (SFA).





3 Key Findings

Here we highlight some key findings across all research activities. Details of our full insights can be found in the full <u>Research Report</u>.

3.1 Modes of Transport



- 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 most uncomfortable and difficult public transport options (buses 86%, trains 82% and taxis/rideshares 81%).
- Autistic people who use the bus tend to travel this way weekly (37%), while trains and taxis/rideshares are used less often.
- Inaccessible services prevent some autistic people from using buses (42%), trains (32%), and taxis/rideshares (14%) at all.

3.2 Challenges

The top challenges experienced using transport, and barriers to travel, for autistic people on trains, buses and taxis/rideshares include:



1. Crowding on platforms and services (90%)

"You're standing next to strangers and breathing in the same air as a lot of people and you can feel their body heat. Then it's also hard to move about and you don't want to bump into anyone."

Autistic woman, aged 18, Bangladeshi, living in an urban area of London.



2. Sensory discomfort or overload (87%)

Lighting, temperature, how things look or feel, strong smells and loud noises all affect the travel experience.







3. Strangers being close or seated beside them (86%)

This can make challenging sensory stimuli even stronger and feel like an invasion of personal space.



4. Unexpected delays and cancellations (85%)

"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, living in a suburban area of Wales.



5. Feeling anxious or unsafe outside the home or in public (81%)

Autistic people may feel anxious about going out, like they're on 'high alert', which can make travel particularly difficult as they're not in control or always able to leave.



6. Struggling to travel without planning first (80%)

Travelling requires lots of planning to feel prepared and in control, and to reduce uncertainty, but there isn't always detailed, accurate, accessible information available when they need it.



7. Feeling rushed by others (76%)

Autistic people may struggle to respond without processing time, or make decisions under pressure when the environment is already overwhelming.

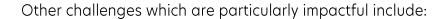


8. Being unable to sit down (74%)

Standing on a moving vehicle (or when waiting) can be difficult, particularly if co-occurring conditions impact physical health.







Being unable to travel independently or without someone with them

Having someone to travel with is not always possible, limits when and where they can travel, and is associated with feelings of guilt and 'failure'.





Having to talk to others

Autistic people can feel pressure and overwhelm or go into shutdown from: needing or being expected to communicate in a certain way, making 'chit chat', fear of conflict and social rejection or being confused by social rules.

Being discriminated against by passengers and staff

Some people don't realise or believe that someone is autistic; there's a lack of public empathy which comes from not appreciating the difficulties they face or misunderstanding their distress as aggression; and some autistic people have faced abuse and discrimination when using transport which has a lasting impact on their confidence to travel alone again.





Lack of accessible information

In busy places there is too much information to process; they may not feel comfortable or able to approach staff with queries; and information at every stage of their journey including online sources can be confusing, inaccurate or unavailable when they need it.

Pressure to 'mask' autistic behaviour

There's a lack of public understanding, and many autistic people are judged critically by other passengers why they have panic or meltdowns. Often autistic people feel they must hide their autistic behaviour or useful coping mechanisms such as stimming which can cause exhaustion and distress.





Being unable to move freely or leave mid-journey

Many autistic people say they need a break from travelling in order to cope, but this isn't possible on all modes of transport and has ticket implications.





3.3 Impacts of Difficult Travel

The top impacts of difficult travel and lack of transport accessibility for autistic people include:

- 1. Being anxious about travel even before their journey starts (71%)
- 2. Having to spend more time recovering or 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 and 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%)

Other impacts which we observed autistic people experiencing included:

- 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.

3.4 Industry Perspectives

Discussions with transport professionals highlighted:

- variance in autism understanding and autism and wider disability training;
- no set guidance on autism compared to other disabilities or needs;
- an appetite for change but this depends on location and travel company;
- conflicting priorities (such as different passenger needs) and restrictions (such as budget and legal requirements);
- useful support available which is not well-known or communicated;

Transport professionals felt that to really make a difference there needs to be:

- collaboration and information sharing;
- a culture shift in the industry.

[Research discussion and limitations can be found in our full Research Report.]





4 Recommendations

All qualitative information captured throughout the project was coded and grouped into common themes (thematic analysis). We developed and refined these themes to draw out specific recommendations, checking also that it reflected quantitative findings.

This process allowed us to be confident that our recommendations are grounded in the data. Each theme generated recommendations for autistic people, their families or friends, transport providers and the general public. (Some suggestions may already exist in some settings but not others.)

Note, much of our commentary around recommendations refers to train and bus travel, as we gained the most insight on these ways of travelling. We know, however, that many challenging experiences are felt regardless of transport mode and therefore many recommendations here can be adopted across the industry.

4.1 Travel Support

Service providers should try to offer:

- Travel assistance which is easy-to-arrange, including support at travel facilities, stations and onboard vehicles.
- Clearly identifiable dedicated support staff.
- Clear information on one place (e.g. website) to explain what support is available for autistic passengers and how to access it.
- Clearly visible support points in public spaces and stations of where to go for trusted, trained support.
- Autism friendly accredited service.
- Collaborative working with travel training scheme providers.
- Discounted rates on accompanying carer tickets where possible.
- Openness to ask what someone needs even if they're not sure if they're autistic.
- Sensory regulation tools such as ear defenders, capped hats, fans.
- Communication cards for passengers to let staff know their needs.
- A supportive manner including:
 - sympathy and support if recovery time is required;
 - patience and not rushing them;
 - help in making decisions, particularly when there are unexpected changes;
 - a safe space should an autistic person experience shutdown, meltdown or panic;
 - somewhere less crowded or noisy;
 - giving options to get information and help without talking;
 - assistance and benefit of the doubt if an autistic person travels with an incorrect ticket type;
 - o reassurance.







Autistic transport users could also maintain contact with a family member or friend whilst travelling, for additional reassurance and help if things do not go to plan.

4.2 Accessible Information

Service providers should try to offer:

- Travel announcements delivered via static screens as well as through auditory announcements.
- Indication of live service capacity available through official sources.
- Clear signs to help them to know where to queue, where carriage doors open, which zones to wait in for quiet carriages.
- Clearer signposting at stations, particularly towards the nearest exit (when the priority is exiting quickly), or particular exits.
- Improved visual maps.
- Information across multiple services combined into a single official source wherever possible.
- Advance notice of changes to timetables and routes including seasonal changes.
- Reasons for delays and cancellations wherever possible.
- Clear visual instructions on how to use ticket machines and barriers or someone to ask.
- Simplified ticket selection
- Travel information in accessible formats including easy-read information
- Easy to understand timetables
- Contact details for station services and travel enquiries
- Virtual walk-throughs (more widely available and better advertised)

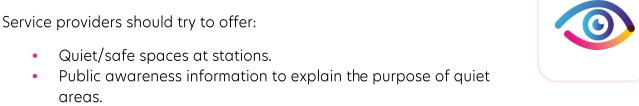
Developers of transport apps should consider prioritising:

- Simplified or catered interface for those who communicate differently.
- Advanced information about planned changes, and live information e.g. delay times that are accurate, reliable and consistent.
- Online booking and ticket purchases for all transport types.

4.3 Sensory Adaptations

- Pre-bookable quiet train carriages or adapted carriages that consider wider sensory overwhelm (lighting, textures).











- More electric buses for quiet travel.
- Less visually and audibly overwhelming stations or waiting areas.
- Well maintained and regularly cleaned vehicles, with the ability to report problems easily.
- Individual seating on transport, or a way of better maintaining personal space whilst seated.
- the option of taking a break on a journey on the same ticket.
- Clear messaging about the barriers and limitations of recommendations they can't
- Inclusion of autistic people in the future design of transport and waiting spaces.
- 'Next-best' alternatives to space and sensory accommodations where building restrictions limit change.

Autistic people could also use:

- Headphones or noise cancelling items.
- Regulatory and comfort items (such as fidget tools, puzzles, or food).
- Controlled distraction by engaging in a pleasurable activity, for example, reading.

4.4 Autism Understanding

Transport providers should aim to offer:

- Public campaigns and information about:
 - o autism;
 - social and communication differences;
 - meltdowns;
 - sensory overload;
 - stimming and self-soothing behaviours;
 - o accommodations that can be made by them.
- Digital advice and guidance on their websites.
- High quality autism training involving autistic people.
- A named autism champion in their staff team who advocates for autistic users.
- Training time reading case studies and real stories that bring the travel experiences to life.
- Ride-along journeys with autistic people to better understand the travel experiences autistic users face.
- Work with autistic consultants to design and evaluate any initiatives.
- Support public awareness of hidden disabilities and the challenges on different modes of transport.
- Promote and share existing schemes more widely.
- Participate in industry forums and working groups to share autism knowledge and move through barriers to changing their services in the recommended ways.











Transport providers should try to offer:

- Planning checklists and resources.
- Advance notice of engineering works or strike action or closures.
- Clear, accessible, online announcements of any changes or replacement plans, cancellations and delays.
- Improved consistency between transport vehicles to reduce uncertainty from every vehicle and carriage being different.
- Travel training schemes for autistic people to help with planning and testing out new journeys.
- Simplified ticket schemes and purchasing options, maintaining the ability to buy tickets from a manned ticket office, automated machine and online wherever possible.

Autistic people can:

- Access live trackers to know exactly what is happening in real time.
- Emotionally prepare for a journey by actively taking time to relax beforehand and reflect and recover afterwards.
- Practise journeys to increase familiarity and reduced unpredictability.
- Prepare by learning routes and understanding journey timings to increase confidence.
- Use quieter travel times where this is possible.
- Choose mode that provides 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.
- Have an emergency plan covering what they could do if something went wrong during the journey.
- Keep things the same where possible by keeping to preferred mode, sitting in the same seat, taking the same route to the station.







5 Conclusions

This research is the first of its kind, addressing a significant gap in evidence, capturing a wealth of experiences, and being truly autistic-led in its delivery. It has provided vital insight into autistic people's experiences of using transport and making journeys, but has also proposed evidenced and workshopped ideas for change, for key stakeholders. In line with our funder the Motability Foundation's proactive approach to transport and disability, this research helps bridge the gap between autistic need and published research.

By working together to understand challenges for autistic people, and facilitate positive change, autistic people can make comfortable journeys and improve their quality of life. Empowering Autistic Travel.

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7.1 Acknowledgements

We would like to thank every participant for their valuable contribution to this project - your time and effort has been much appreciated and has helped to grow understanding of how autistic people can be better supported to use transport.



We also give heartfelt thanks to our 8 co-design group members who have dedicated their time to guiding the research, verifying findings and sharing their personal experiences with travel.



We would also like to thank the Motability Foundation for their generous support. The Motability Foundation funds, supports, researches and innovates so that all disabled people can make the journeys they choose. It oversees the Mobility Scheme and provide grants to help people use it, providing access to transport to hundreds of thousands of people a year.

7.2 National Autistic Society



The National Autistic Society exists to transform lives, change attitudes, and create a society that enables autistic people to live a fulfilled life on their terms. In 1962, we formed the world's first ever autism-specific school and today we operate four schools, educating around 350 autistic pupils per year. We provide support, information, and practical advice for more than 700,000 autistic adults and children in the UK, as well as their three million family members and carers.

We also work to influence local and national government, and collaborate with employers, other groups and charities, and professionals in healthcare and education, encouraging them to improve standards and embed good practice. On a larger scale, we transform society by improving public understanding of autism, campaigning for change to laws affecting autistic people, and advocating for greater acceptance of and respect for autistic people.





7.3 Resources



The full Research Report is on our website (with more Empowering Autistic Travel resources to be added Spring/Summer 2025)

www.autism.org.uk



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