

# Empowering Autistic Travel

A Journey to Accessible Transport  
Through Participatory Research

Research Report

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# Contents

|       |                                                                        |           |
|-------|------------------------------------------------------------------------|-----------|
| 1     | <b>Abstract .....</b>                                                  | <b>1</b>  |
| 1.1   | <b>Co-design and Participation .....</b>                               | <b>1</b>  |
| 1.2   | <b>Rapid Review .....</b>                                              | <b>1</b>  |
| 1.3   | <b>Scoping and Insight Surveys .....</b>                               | <b>1</b>  |
| 1.4   | <b>Interviews – Autistic People and Parents/Carers .....</b>           | <b>2</b>  |
| 1.5   | <b>Focus Groups and Workshops – Transport Professionals .....</b>      | <b>2</b>  |
| 1.6   | <b>Recommendations .....</b>                                           | <b>3</b>  |
| 1.7   | <b>Limitations .....</b>                                               | <b>3</b>  |
| 1.8   | <b>Conclusion .....</b>                                                | <b>3</b>  |
| 2     | <b>Introduction.....</b>                                               | <b>4</b>  |
| 2.1   | <b>Rationale for the Study .....</b>                                   | <b>4</b>  |
| 2.1.1 | Why Autism? .....                                                      | 4         |
| 2.1.2 | Why Transport? .....                                                   | 5         |
| 2.2   | <b>Aims and Scope .....</b>                                            | <b>5</b>  |
| 2.3   | <b>Rapid Review .....</b>                                              | <b>6</b>  |
| 2.3.1 | Summary of Published Research .....                                    | 6         |
| 2.3.2 | Summary of Published Resources .....                                   | 7         |
| 2.3.3 | Summary of the Lived Experience of Autistic Bloggers or Vloggers ..... | 8         |
| 3     | <b>Methodology.....</b>                                                | <b>9</b>  |
| 3.1   | <b>Participatory Approach.....</b>                                     | <b>9</b>  |
| 3.2   | <b>Stakeholder Mapping and Recruitment.....</b>                        | <b>9</b>  |
| 3.3   | <b>Ethical Considerations.....</b>                                     | <b>10</b> |
| 3.4   | <b>Mixed Methods Approach.....</b>                                     | <b>10</b> |
| 4     | <b>Data Collection, Analysis and Findings.....</b>                     | <b>11</b> |
| 4.1   | <b>Scoping Survey .....</b>                                            | <b>11</b> |
| 4.1.1 | What we did.....                                                       | 11        |
| 4.1.2 | Who we heard from.....                                                 | 11        |
| 4.1.3 | What the scoping survey data tells us .....                            | 12        |
| 4.2   | <b>Co-Design Group (CDG) .....</b>                                     | <b>14</b> |
| 4.3   | <b>Insight Survey .....</b>                                            | <b>15</b> |
| 4.3.1 | What we did.....                                                       | 15        |
| 4.3.2 | Who we heard from.....                                                 | 16        |
| 4.3.3 | What the insight survey data tells us.....                             | 17        |
| 4.3.4 | What further analysis could tell us.....                               | 27        |
| 4.4   | <b>Travel User Interviews .....</b>                                    | <b>27</b> |
| 4.4.1 | What we did.....                                                       | 27        |
| 4.4.2 | How we analysed.....                                                   | 28        |



|       |                                                               |           |
|-------|---------------------------------------------------------------|-----------|
| 4.4.3 | What the interview data told us .....                         | 29        |
| 4.5   | <b>Transport Professional Focus Groups.....</b>               | <b>32</b> |
| 4.5.1 | What we did.....                                              | 32        |
| 4.5.2 | Who we spoke to.....                                          | 33        |
| 4.5.3 | What we found.....                                            | 34        |
| 4.6   | <b>Solution Testing Workshops .....</b>                       | <b>35</b> |
| 4.6.1 | Who we spoke to.....                                          | 35        |
| 4.6.2 | What we did.....                                              | 35        |
| 4.6.3 | What we found.....                                            | 36        |
| 4.7   | <b>Outputs Survey .....</b>                                   | <b>38</b> |
| 4.7.1 | What we did.....                                              | 38        |
| 4.7.2 | Sample.....                                                   | 38        |
| 4.7.3 | What we found.....                                            | 38        |
| 5     | <b>Discussion .....</b>                                       | <b>39</b> |
| 5.1   | Addressing the Research Question: .....                       | 39        |
| 5.2   | Findings in Relation to Existing Literature:.....             | 39        |
| 5.3   | Findings in Relation to Theories:.....                        | 39        |
| 5.4   | Findings in Relation to Practice:.....                        | 40        |
| 5.5   | Why This Is Significant: .....                                | 40        |
| 6     | <b>Recommendations .....</b>                                  | <b>41</b> |
| 6.1   | Travel Support.....                                           | 42        |
| 6.2   | Accessible Information .....                                  | 45        |
| 6.3   | Sensory Adaptations .....                                     | 47        |
| 6.4   | Autism Understanding.....                                     | 48        |
| 6.5   | Reduce Uncertainty .....                                      | 52        |
| 7     | <b>Limitations and Challenges .....</b>                       | <b>53</b> |
| 8     | <b>Conclusions.....</b>                                       | <b>54</b> |
| 9     | <b>Appendices .....</b>                                       | <b>56</b> |
| 9.1   | Appendix 1: Rapid Review Search Strategy .....                | 56        |
| 9.2   | Appendix 2: Ethical Guidelines and Principles.....            | 57        |
| 9.3   | Appendix 3: Outcomes of Co-design Group Activities.....       | 58        |
| 9.4   | Appendix 4: Themes from Interview Analysis.....               | 61        |
| 9.5   | Appendix 5: Example Visual Representation of the Themes ..... | 65        |
| 10    | <b>Further Information .....</b>                              | <b>66</b> |
| 10.1  | Acknowledgements.....                                         | 66        |
| 10.2  | National Autistic Society.....                                | 66        |
| 10.3  | Resources.....                                                | 67        |



# 1 Abstract

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.

## 1.1 Co-design and Participation

This project was led by autistic people. Along with our two autistic project leads, we enlisted a co-design group of 8 autistic people. We then captured experiences of a large number of autistic participants through surveys, and more in-depth views through interviews. We 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, transport professionals and travel accessibility experts. This resulted in a rich combination of qualitative and quantitative data.

## 1.2 Rapid Review

There is a lack of quality, UK-based, user informed research on this topic. What we found mostly focussed on children and use of technology in transport, with small sample sizes. We also collated and summarised professional guidance, and vlogs/blogs from autistic people. These were also limited, with autistic people demonstrating some common challenges with travel, as well as self-help strategies to reduce barriers.

## 1.3 Scoping and Insight Surveys

To refine our research focus, we surveyed 560 autistic people, family members, friends and support professionals about travel usage and barriers. They told us that:

- Other than walking and driving - train, bus and taxi/rideshare were the most common modes of travel.
- These travel modes were also the most problematic, with wide-ranging challenges.
- Impact of travel barriers included increased anxiety, exhaustion, and missing out on events, experiences and appointments.





We later surveyed a diverse sample of 3375 autistic people and those supporting an autistic person, asking more in-depth questions about barriers and impact but also potential solutions to travel.

They told us that:

- the biggest challenges to train, bus and taxi/rideshare users were crowding, sensory overwhelm, and unexpected changes to a journey;
- travel barriers could be addressed through changes to the environment, improved information, less reliance on social interaction, and better autism understanding from others.

## **1.4 Interviews – Autistic People and Parents/Carers**

We interviewed a total of 20 autistic people and parents/carers. This allowed for greater exploration and understanding of participants' experiences. These discussions echoed the surveys, and told us that:

- sensory environments (crowding, lighting, temperature, smells, bright lights etc.) negatively impact the travelling experience;
- the need to interact with others, and societal expectations of how to interact (including reliance on verbal communication) can be difficult, confusing and exhausting;
- uncertainty and unexpected change to journeys can cause discomfort, anxiety and fatigue;
- being misunderstood, judged or discriminated against whilst travelling impacted their confidence in going out, and led them to mask, which is detrimental to wellbeing;
- lack of clear, reliable information (and difficulties approaching staff for help) can also impact confidence and cause overwhelm;
- difficult journeys can impact wellbeing and independence, and may cause a sense of failure.

## **1.5 Focus Groups and Workshops – Transport Professionals**

We consulted with 22 transport professionals, including accessibility managers for several train services. They told us that:

- autism understanding (and training) varies widely;
- there is an appetite for change but this also varies widely;
- there are limitations to possible physical space adjustments, as well as financial constraints;
- there are conflicting passenger accessibility needs to consider;
- some travel support exists but is not well communicated.



## 1.6 Recommendations

Through a process of analysing our insight, and identifying themes (thematic analysis), we arrived at evidence-based, realistic recommendations for autistic people, families, transport professionals, and the general public. The main themes were:

- support for autistic travellers;
- accessible information;
- sensory adaptations;
- autism training;
- reducing uncertainty.

## 1.7 Limitations

Whilst the project had a large and diverse participant pool, within the timeframe and scope we were unable to:

- engage with taxi/rideshare representatives;
- focus on more transport modes (e.g. ferries; coaches);
- run a control study with non-autistic people;
- meaningfully engage with some hard to reach autistic people such as those with English as a second language, lack of access to digital technologies, or very complex needs.

## 1.8 Conclusion

This was a thorough and robust piece of participatory research, that addressed the evidence gap on autism and transport. 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.



## 2 Introduction

This project was conducted by the National Autistic Society's Research team, and funded by the Motability Foundation. The funding required us to explore accessible travel for autistic people, enabling a piece of high-quality user research, delivered and guided by autistic people.

This report describes the research method, findings and recommendations of the project. (Visit our website for a shorter [Research Overview](#).)

### 2.1 Rationale for the Study

#### 2.1.1 Why 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.

In addition, many autistic people experience heightened anxiety, and challenges with executive functioning (such as planning, memory, organisation and self-regulation). In combination, these traits and differences can significantly impact an autistic person's everyday activities and interactions.

Compounding this, autistic people routinely face societal judgement and discrimination, due to lack of public understanding, or negative attitudes towards difference. Whilst society is slowly changing, there is still a very long way to go towards widespread understanding and acceptance.



### 2.1.2 Why Transport?

The topic of transport is relevant to a number of the National Autistic Society's beliefs, ambitions and priorities, outlined in our [organisational strategy](#).

Specifically, it relates to our vision of a society where:

- Public spaces are open and accessible to all, regardless of sensory needs or communication differences, with adjustments built in from the start.
- Autistic people are empowered to make choices about their own life and shape the world around them – whether that's through their daily choices about where to go and what to do, or creating change in wider society.

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 also know that a disproportionate number of autistic people face social isolation and loneliness. Whilst many autistic people enjoy spending time alone, loneliness is different. It is a negative experience that can occur when autistic people do not have fulfilling connections with other people. Loneliness among autistic people may be exacerbated by barriers to accessing transport.

## 2.2 Aims and Scope

The project was framed by the Motability Foundation's intended outcomes:

- improved and increased high quality research on disability and transport;
- increased stakeholder awareness regarding transport challenges for disabled people;
- stakeholder actions driven by knowledge.

The project plan 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.



The project began with a deliberately broad research question:

***What are the key issues that autistic people and their families experience when travelling, how does this impact them, and how can barriers be reduced within particular aspects or modes of travel?***

From insight gained through our rapid review, scoping survey and discussions with our co-design group, the research topic was narrowed down to focus on bus, train and taxi/rideshare travel and was refined to explore:

- transport usage and preferences of autistic adults;
- barriers to comfortable, safe travel;
- which challenges tend to be the most significant for autistic people;
- the impact of difficult travel on autistic people's lives;
- user-led ideas which could make transport more accessible and comfortable for autistic users;
- the appetite and ability of service providers to make autism friendly changes to their ways of working within reasonable constraints.

## 2.3 Rapid Review

We completed a review of published academic research, professional guidance, and lived experience accounts (blogs and vlogs) by summarising key points and assessing the quality of each resource against an established set of criteria. The information from the review strengthened and informed the focus of the study from the identified gaps in research. (For our search strategy see [Appendix 1](#)).

### 2.3.1 Summary of Published Research

There was limited research with the majority of the research projects available undertaken in the US and Australia. Themes identified in the research papers were:

- Identifying and addressing barriers to accessing public (including app development) ([Rezae et. al., 2021](#); [McMeekin et. al., 2020](#)).
- Travel training programmes for autistic ([Pfeiffer et. al., 2024](#); [Glaser et. al., 2022](#))

The majority of research studies had small participant numbers (averaging under 50 participants), very specific geographical areas, reliance on verbal communication, and ability to commute independently.



Some researchers, ([Rezae et. al., 2021](#) and [McMeekin et. al., 2020](#)), identified some of the challenges that autistic people can face when trying to access public transport including:

- safety and spatial awareness;
- anxieties about navigating the journey;
- anxiety about unexpected events (e.g. cancelled trips or diversions);
- sensory sensitivities – increased risk of sensory overload;
- difficulty with trip planning;
- differences in communication skills impacting ability to access support.

One study ([Dirix et. al., 2023](#)), undertook 17 semi-structured interviews about using public bus transport identifying ways to make transport more accessible:

- creating predictability;
- limiting sensory stimuli;
- accessible communication;
- providing training for staff;
- accurate and accessible information.

***“Accessible, safe, and efficient public transport can promote quality of life by positively impacting employment, social participation and healthcare access.”***

***[Dirix et. al. \(2023\)](#)***

### 2.3.2 Summary of Published Resources

There are limited UK-specific resources on autism and transport. The majority focus on campaigns to improve commuting experiences of autistic people, and general non-autism specific advice on travelling with a disability.

One guidance booklet ([Network Rail, 2021](#)) has information for autistic people using trains, including what to expect, how to prepare, and a step by step process from arrival at the station.

Many of the resources, and lived experience resources, were specifically related to (or inspired by trips to) London ([Farad, 2019](#)).





### 2.3.3 Summary of the Lived Experience of Autistic Bloggers or Vloggers

There are limited UK-based lived experience sources available on the topic of autism and transport. Of the sources found, the majority share travel challenges as well as advice on overcoming them.

The commonly identified barriers included ([Lowery, 2017](#); [T Jones, 2017](#); [Aoife, 2018](#)):

- unpredictability of the environment and people around you;
- unexpected changes to travel;
- anxiety about the journey;
- sensory concerns;
- social anxiety;
- difficulty with journey planning and managing the journey.

*"I find the external environment to be so saturated and stimulating, then to combine that with the stress of travel, and the fact that anything can change or go wrong, can literally be enough to prevent me from going in the first place."*

*[Amatina \(2023\)](#)*

The lived experience sources shared the following tips for overcoming challenges ([Lowery, 2020](#); [Jones, 2017](#); [Amatina, 2023](#); [Gandecha, 2018](#); [Aoife, 2018](#)):

- planning the journey in advance;
- travelling during off-peak, quieter periods or avoiding non-essential journeys;
- bringing sensory tools;
- travelling with someone;
- using apps that have timetables and live information;
- asking for help when needed.

Information was sparse, and research limited in quality. This demonstrated a clear need for user research which:

- is guided by autistic people;
- is not solely child-focussed;
- is significant in sample size;
- is representative (considering intersectionality, and typically under-represented autistic groups);
- aligns with ethical governance;
- is impactful.



## 3 Methodology

### 3.1 Participatory Approach

This project has been genuinely informed by autistic people and has prioritised their experiences. The core delivery team are autistic, but the project also utilised a Co-Design Group (CDG) to steer and shape the work. We worked with eight autistic group members on tasks such as planning our insight gathering, interpreting findings, and refining priorities and outputs.

We created opportunities to hear many autistic voices through our surveys and interviews, and we sought valuable insight from other stakeholders including parents/carers, friends and families of autistic people, and transport professionals (autistic and not autistic).

Our approach to participation and stakeholder engagement has ensured that the final outputs are shaped by those experiencing transport challenges, as well as transport providers.

### 3.2 Stakeholder Mapping and Recruitment

We identified key audience groups who are involved in using, providing and commissioning transport for our chosen modes. We identified the key stakeholders to target and developed an engagement plan to guide our recruitment of participants.

We used an ongoing recruitment form to gauge interest in retention and to invite participants to subsequent research activities, such as a follow up interview. The recruitment form was shared via social media at the start of the project, and it was modified to retain interested parties for later stages of the research.

We wanted to involve typically underrepresented autistic people in the project, including those who are of the global majority, gender diverse, have co-occurring health conditions, or have limited or no speech.



### 3.3 Ethical Considerations

We are committed to safeguarding the wellbeing of participants and maintaining good ethical practice. We ensured that this project complied with a professional code of ethics and ethical guidelines, specifically for vulnerable adults (For more information, please see [Appendix 2](#)).

### 3.4 Mixed Methods Approach

We used quantitative and qualitative data collection methods to gather insight across several research activities [Table 1].

**Table 1 – An outline of the methods used**

|    | Activity                                                                                                                                                                          |
|----|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. | <b>Rapid review</b> - review of current research, professional resources and vlogs/blogs of lived experiences                                                                     |
| 2. | <b>Scoping survey</b> - a small survey to capture issues to shape research aims                                                                                                   |
| 3. | <b>Co-Design Group (CDG)</b> - an autistic co-design group to meet regularly to make study design decisions                                                                       |
| 4. | <b>Insight survey</b> - a large scale survey to collect quantitative and qualitative data about autistic travel experiences                                                       |
| 5. | <b>Travel user interviews</b> - semi-structured interviews with autistic people and parents/carers representing autistic people                                                   |
| 6. | <b>Transport professional focus groups</b> - to discuss the professional perspective on autistic travel challenges, including rail providers, researchers and accessibility leads |
| 7. | <b>Solution testing workshops</b> - to discuss the 'user ideas' with professionals and assess them for suitability, feasibility and acceptability                                 |
| 8. | <b>Output survey</b> - to collect data about which formats and channels we should use to share findings and further resources                                                     |



## 4 Data Collection, Analysis and Findings

### 4.1 Scoping Survey

#### 4.1.1 What we did

We conducted a survey, at the start of the project, to capture travel issues most significant and relevant to autistic people. To understand travel in the context of autism, we also gathered demographic information including:

- age;
- socio-economic status;
- level of support needs;
- co-occurring conditions.



We promoted the survey via our social media channels, and incentivised participants to complete the scoping survey using a £50 voucher prize draw.

#### 4.1.2 Who we heard from

This survey was completed by 466 autistic people and 94 people reporting on behalf of an autistic person (relatives, friends, carers and supporting professionals).

Of those 560 autistic people:

- 59% were female;
- 34% male;
- 8% other genders including non-binary, genderqueer and agender people.

The average age of participants was 39 years with a range from 9-73 years and included autistic people with:

- a range of communication differences including intermittent, unreliable, or no speech;
- varying support needs;
- co-occurring disabilities;
- mixed driving status.



Participants were from all regions of the UK but there were more from the South East and London, and few from Northern Ireland. 1 in 10 autistic people were of the global majority with:

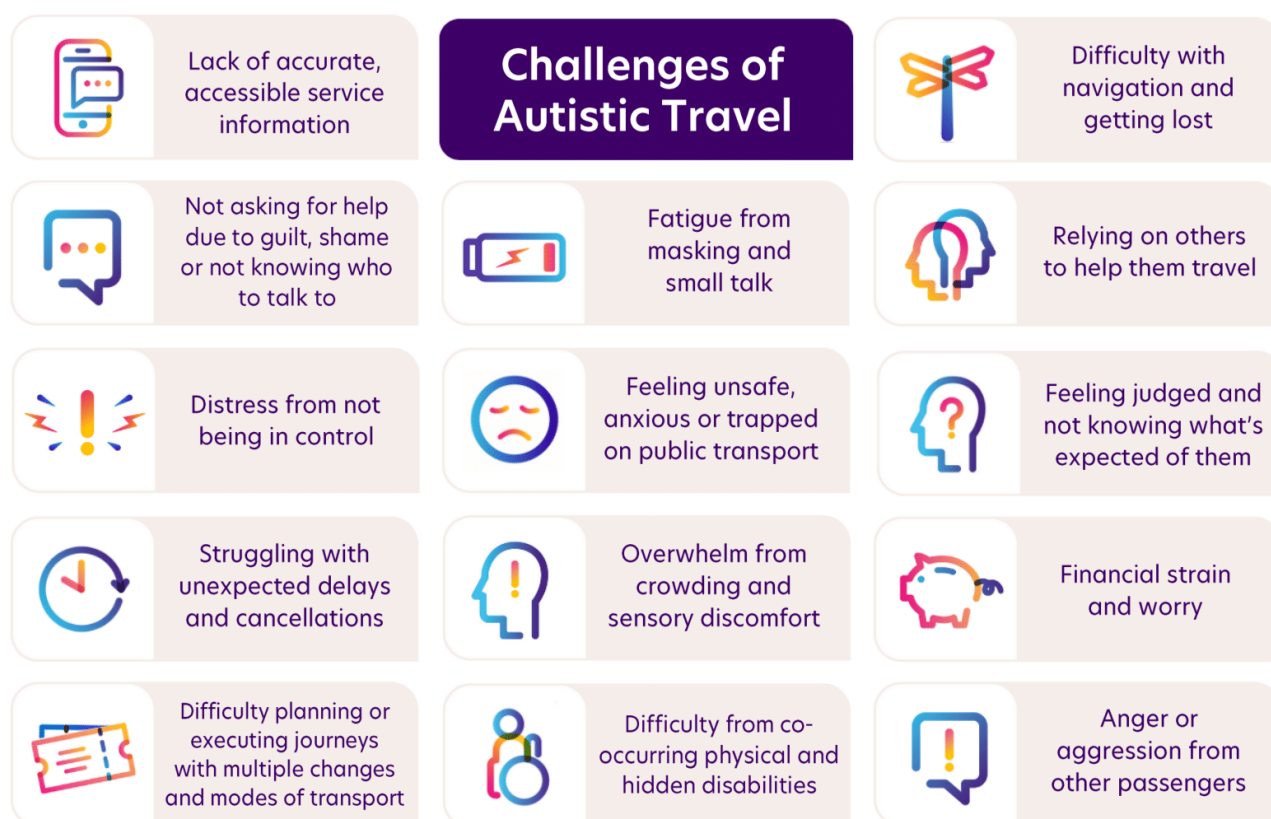
- 5% being from mixed or multiple ethnic groups;
- 3% Asian or Asian British;
- 2% Black, Black British, Caribbean or African;
- 1% other non-white ethnicities.

Based on this data we changed our recruitment approaches for the insight survey, to ensure a more representative sample.

### 4.1.3 What the scoping survey data tells us

The scoping survey provided us with information about autistic peoples' transport use, the challenges they face when travelling [Figure 1], and the impact those travel challenges have on them [Table 2].

Figure 1 - Common challenges autistic people experience when travelling



Autistic people most commonly travel on foot, with 96% walking, and 39% reporting they walked daily. Car travel was also common with 44% reporting they drive a car weekly and 32% being driven by someone else on a weekly basis. Other commonly used methods of transport include trains (82%), buses (72%) and taxis/rideshares (38%).

The survey also revealed less-used modes of transport, with 75% of respondents never cycling and 68% never using coaches. 74% report never using trams, though clearly this is a geographically limited mode.

The data also shows that whilst many autistic people are reliant on buses and trains to get around, they also find them the most difficult forms of transport to use. 86% reported they find buses uncomfortable and difficult to use, whilst 82% reported the same for trains. Similarly, 81% reported using taxis and rideshares as uncomfortable and difficult. Barriers and challenging travel experiences have a great impact on autistic people's access to services and opportunities for work and leisure [Table 2].

**Table 2 - Negative impacts of difficult travel and lack of transport accessibility for autistic people**

| Impacts                                                                                       | Rate |
|-----------------------------------------------------------------------------------------------|------|
| Being anxious about travel even before their journey starts                                   | 71%  |
| Having to spend more time recovering or resting                                               | 68%  |
| Having more meltdowns or sensory overload while travelling or when reaching their destination | 62%  |
| Being anxious about trying other forms of transport                                           | 58%  |
| Missing out on events or experiences they want to go to                                       | 54%  |
| Worrying about getting to medical appointments easily and on time                             | 52%  |
| Being exhausted or overloaded when they reach their destination                               | 51%  |
| Only being able to travel at quiet times, even if this doesn't suit them                      | 49%  |
| Missing out on accessing hobbies and interests                                                | 46%  |
| Worrying about their future                                                                   | 44%  |
| Feeling judged by others                                                                      | 44%  |
| Struggling to go out alone or without help                                                    | 44%  |
| Missing out on seeing friends and family                                                      | 41%  |
| Spending more money than they intend to, avoiding busy routes or modes of transport           | 37%  |
| Feeling more isolated                                                                         | 37%  |
| Feeling lonelier                                                                              | 36%  |
| Missing out on being involved in their community                                              | 34%  |





|                                                                                      |     |
|--------------------------------------------------------------------------------------|-----|
| Finding it hard to find suitable jobs which they can get to                          | 34% |
| Feeling unsafe travelling                                                            | 33% |
| Worrying about getting groceries and essentials or not being able to go out for this | 32% |
| Being unable to travel far from home                                                 | 30% |
| Relying on people coming to them                                                     | 29% |

## 4.2 Co-Design Group (CDG)

Early on in the project we recruited an autistic led co-design group, to work with us throughout. They would collaborate with us and challenge our assumptions, biases and working methods.

To recruit group members, we advertised the opportunity through our social media channels, and to our already established pools of autistic participants who had previously expressed an interest in research opportunities. We provided a clear brief, outlining the role and commitment involved as a CDG member.

Our screening process ensured we recruited quickly, fairly and transparently, with representative diversity. Given the limited timeframe and resources, we required group members to have a good understanding of English language, and to be able to give informed consent. Other recruitment criteria included:

- diagnosed autistic;
- uses public transport (at least once a month);
- aged 18 or above;
- is able to access Microsoft Teams (with support if needed);
- lives in the UK.

We screened demographic details, answers to our accessibility questions and expressions of interest statements. The recruitment survey could be completed online or via a phone call.

As the UK's largest autism charity, we were able to establish a group reflective of the diverse autistic population. Autistic people, like non-autistic people, are all very different with unique experiences, strengths, and challenges. Intersections of ethnicity, gender, co-occurring conditions, and other factors also influence identity and individuality, which is why diversity of the CDG was essential to our participatory research method.

The group who assembled to support our research reflected our sample's varied geographical locations (including urban and rural), genders, ethnicities, ages,



co-occurring conditions, support needs, communication preferences, driving abilities and typical transport use. Due to the lack of research involving people who are minimally verbal or have high support needs, we prioritised such individuals for inclusion alongside people of the global majority and rural communities.

We asked our new members to help shape the format of our CDG meetings and, on their suggestions, ensured that engagement was meaningful and accessible for all. Examples of accommodations included use of instant messaging to contribute to discussions, adding thoughts via email retrospectively, providing resources in advance, and low contrast documents. The CDG were paid for their role in the research at the rate of £25 per project hour, including individual document reviews and group meetings.

In an initial CDG meeting we proposed our project approach and presented draft materials to 8 autistic people to gather their opinions on accessibility, areas of focus and questioning style. We amended our plan and resources according to their feedback. Following the meeting, we shared a final project summary with group members including a detailed timeline, engagement plan and workshop session plans. We adapted our original plan for five main workshops into more, but shorter, meetings, on request of the CDG. We emailed project updates periodically between sessions.

It was important that the CDG shaped the study and influenced the decisions from design through to dissemination. The CDG were consulted through a regular schedule of discussion and review activities, the outcomes of which directly affected every stage of the project (for more detail see [Appendix 3](#)).

## 4.3 Insight Survey

### 4.3.1 What we did

We designed an insight survey with the CDG which included open and closed questions to generate both quantitative and qualitative data. We offered a £100 voucher prize draw as an incentive and distributed it via social media advertisements, and email dissemination in line with our stakeholder mapping.



The insight survey focused on train, bus and taxi travel and was completed by autistic people or on behalf of autistic people by their relatives, carers, friends or supporting professionals. The questions explored how autistic people use transport and what challenges they face.



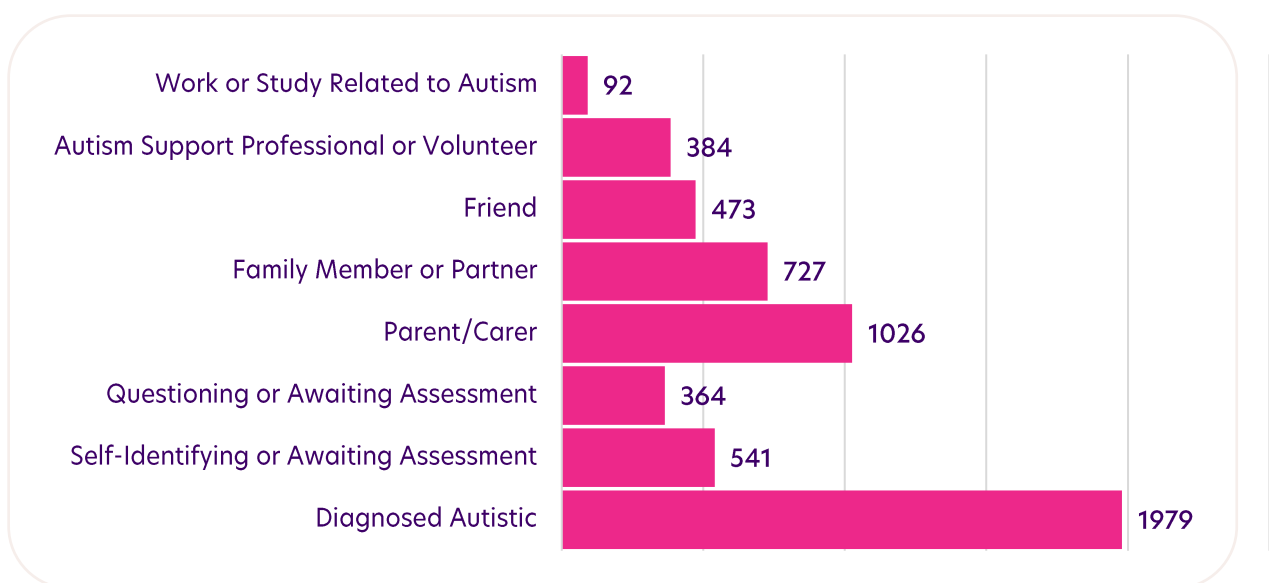
The data facilitated a greater understanding of the travel modes, challenges and impacts of those challenges. The data also showed how autistic people would like to be supported and their ideas for change. Preliminary analysis of the insight survey informed the interview topic guide.

Use of the ongoing recruitment survey pool, along with new social media recruitment meant that we could implement stringent selection criteria to recruit participants with diverse support needs, ethnicities, genders, ages and localities.

### 4.3.2 Who we heard from

We had 3375 valid survey responses. Each response represented an autistic person and 80% of responses were first person accounts from a mix of diagnosed and self-identifying autistic people [Figure 2].

Figure 2 – Participants' connections to autism (multiple choice)



Participants were from all regions of the UK but there were more from the South East and London, and lower representation from Northern Ireland, the North East and Wales.

The survey respondents represented autistic:

- women (60%);
- men (29%);
- non-binary people (7%);
- other genders (2%).



Over 9 in 10 autistic people we sampled reported that they have co-occurring conditions, including:

- Anxiety disorders (36%)
- Depression (34%)
- ADHD (33%)
- Asthma (18%)
- Hypermobility (16%)
- Chronic pain (14%)
- Chronic fatigue (13%)
- Dyspraxia (13%)
- Dyslexia (13%)
- OCD (10%)
- Learning disability (10%)

Some of our participants also had deafness or partial hearing loss, diabetes, heart conditions, wheelchair use and other health considerations. Most autistic people report that their additional conditions make travel even more challenging, affirming that there is great value to approaching autistic accommodations from an intersectional perspective.

The survey explored the impact that difficult travel has on autistic people as well as the intersectional experiences of travel for autistic people with high support needs, additional health considerations and of the global majority.

### **4.3.3 What the insight survey data tells us**

The insight survey provided us with information about:

- the modes of transport used;
- the challenges faced by autistic people using transport;
- the impact of these challenges;
- ideas for change.

## **Modes of Transport**

We measured which transport modes our autistic sample tend to use [Table 3] and how often [Figure 3].

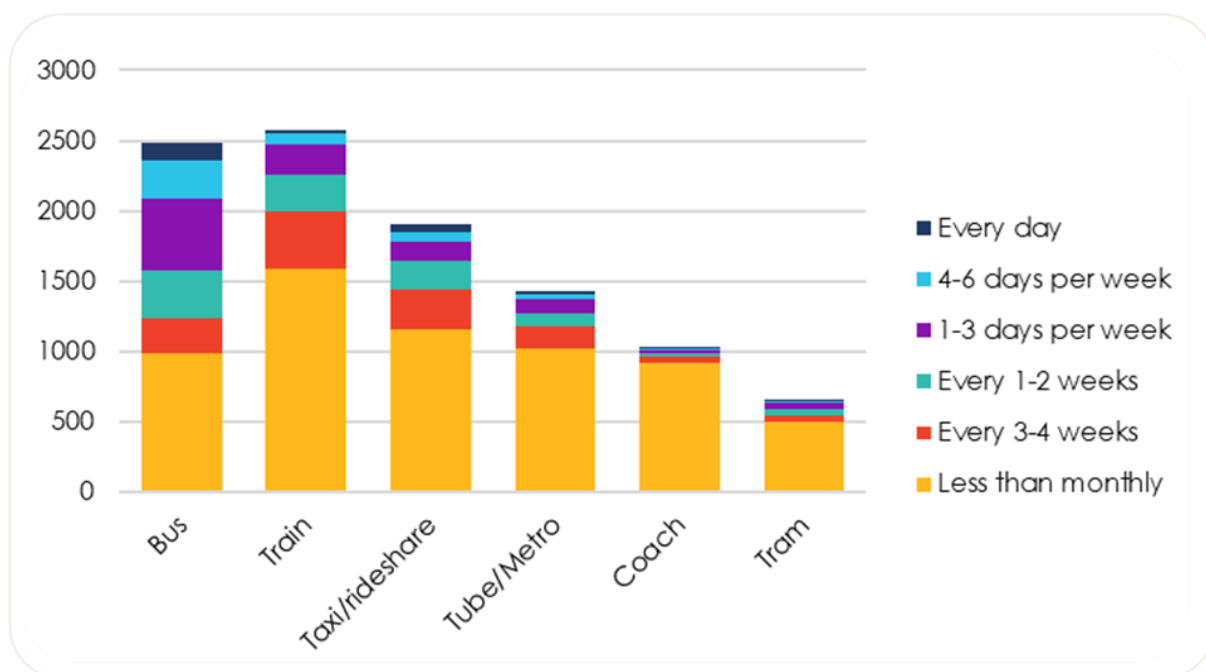
Buses were reportedly used most frequently, usually on a weekly basis (37%), with taxis and rideshares most likely used less than monthly (61%), and trains mostly used infrequently (62%).



**Table 3 - How autistic people tend to travel**

| Mode           | % who use | % who never use |
|----------------|-----------|-----------------|
| Train          | 78        | 22              |
| Bus            | 73        | 27              |
| Taxi/rideshare | 56        | 44              |
| Tube/Metro     | 43        | 57              |
| Coach          | 30        | 70              |
| Tram           | 20        | 80              |

**Figure 3 - Autistic people's frequency of travel across various transport modes**



Most autistic people who don't use buses report that it's because they are inaccessible (42%), or they choose to drive instead (41%).

Trains are similarly not used because of inaccessibility (32%) though high costs are also a strong factor (32%) and a lack of local availability is another (15%).

For taxis and rideshares, cost is the biggest reason people may not use them (47%) along with a preference for other alternatives like driving (29%) and public transport (25%). Some also do not use taxis because they find them inaccessible (15%) though as above, this reason is more common for other transport modes.



Other reasons given that prevent people from using public transport include:

- Anxiety and fear
- Too many people
- Abuse, discrimination and trauma from drivers and other passengers
- Needing more control over their journey
- Unreliability of services
- Protection from disease / COVID-19
- Overwhelming sensory environments, particularly noise, smells and cleanliness
- Agoraphobia
- Not needing to use transport (e.g. working from home)
- Motion sickness, wheelchair use, OCD, chronic fatigue and other health concerns

## Challenges

The data tells us that autistic people face specific challenges when using trains, buses and taxis. Similar to the above reasons that prevent travel, they reported that they are frequently concerned by difficult sensory environments, proximity to other passengers, finding suitable seating, social pressures, managing plans and changes, receiving accessible information and feeling unsafe [Table 4].

**Table 4 - Challenges experienced using transport and barriers to travel for autistic people on trains, buses and taxis/rideshares**

| Challenges                                              | Rate |
|---------------------------------------------------------|------|
| Crowding on platforms and services                      | 90%  |
| Sensory discomfort or overload                          | 87%  |
| Strangers being close or seated beside them             | 86%  |
| Unexpected delays and cancellations                     | 85%  |
| Feeling anxious or unsafe outside the home or in public | 81%  |
| Struggling to travel without planning first             | 80%  |
| Feeling rushed by others                                | 76%  |
| Being unable to sit down                                | 74%  |
| Needing a lot of time to plan the journey               | 74%  |
| Strangers trying to talk to them                        | 74%  |
| Lack of comfortable, individual seating                 | 74%  |
| Masking while in public                                 | 73%  |
| Lack of accessible updates when things change           | 72%  |
| Not being in control                                    | 72%  |
| Having to switch between different services or modes    | 72%  |





|                                                                     |     |
|---------------------------------------------------------------------|-----|
| Feeling trapped                                                     | 71% |
| Being misunderstood by others                                       | 71% |
| Discomfort in unhygienic, dirty spaces                              | 70% |
| Lack of live data on how busy the service is                        | 69% |
| Financial cost                                                      | 67% |
| Lack of clear signage                                               | 65% |
| Making polite small talk                                            | 65% |
| Outdated or incorrect information and timetables                    | 63% |
| Difficulty navigating or knowing where they are                     | 62% |
| Unclear social rules and norms                                      | 62% |
| Being unable to move around while travelling                        | 61% |
| Unclear ticket buying and selecting processes                       | 60% |
| Unclear travel information                                          | 60% |
| Feeling unable to approach a stranger for help                      | 60% |
| Having a meltdown                                                   | 60% |
| Not hearing audio announcements                                     | 57% |
| Feeling in danger                                                   | 57% |
| Not knowing who to ask for help                                     | 56% |
| Judgement or discrimination by others                               | 54% |
| Missing their stop from distraction or being lost                   | 51% |
| Running late or being time-blind                                    | 50% |
| Difficulties from another condition (those mentioned earlier)       | 50% |
| Lack of understanding from operators                                | 50% |
| Having to get off early to cope                                     | 49% |
| Finding themselves stranded and unable to finish the journey        | 49% |
| Being unable to take a break in the journey on the same ticket      | 48% |
| Feeling guilty or ashamed of asking for help                        | 48% |
| Being nonspeaking or finding it difficult to speak while travelling | 48% |
| Lack of access to an accessible toilet                              | 42% |
| Being unable to travel independently                                | 40% |

The qualitative survey information echoed the above. We also found that difficulty seeking help arises due to guilt and shame, being nonspeaking, or finding it difficult to talk under pressure while travelling. Some find they need to escape the difficult environment so they get off early, and may find themselves somewhere unfamiliar. Others describe ticket types not allowing for a break in the journey, or being ejected for unintentionally selecting the wrong ticket.



Regarding financial cost, we identified challenges with accessing Personal Independence Payment (PIP) due to complex and aggressive systems. Some also reported being ineligible for PIP Motability support because they had been able to make the occasional journey (however challenging), which further added to the frustration and financial strain of travel.

Several less common but high impact challenges include having a meltdown, judgement or discrimination from others, being nonspeaking and being unable to travel independently. It is important to focus not just on the most common difficulties but also the most impactful, as it is these factors which most prevent autistic people from being able to use transport effectively and complete safe journeys [Figure 4].

Many of these challenges reported are experienced by high numbers of autistic people on trains and buses, though not all apply to taxi/rideshare travel, including crowding, being unable to sit, lack of comfortable seating, lack of accessible updates and having to switch modes.

*“Occasionally he's accidentally bought the wrong ticket for the train and been thrown off by a guard. He's been unable to explain, in that high stress situation, what happened or why he's misunderstanding.*

*He's 25, he looks very cool and you can't tell he has differences, so he looks like somebody who might be trying to cheat their way through the system. He's genuinely made a mistake but they don't accept that because he's a young man.*

*They'll just throw him off the train and he ends up abandoned in a strange place he's never been to before which is very scarring. It took us a long time after that happened to get him to feel confident enough to travel which is a shame.”*

*Parent/carer of an autistic man who is aged 25,  
White and lives in a suburban area in the North West*

The challenges listed are therefore best understood as the greatest challenges with train and bus travel. Though there are distinctions in what makes bus and train travel difficult to use, there is also high consistency in the barriers that autistic people face across both. This suggests that interventions to address challenging travel on buses will be at least moderately useful for train travel as well, and vice versa.



We also queried the similarity of difficulties on these modes with experiences using coaches, trams and tubes/metros. Coach travel is most similar to bus travel (49%) though some of the challenges from trains (25%) and taxis (23%) also apply on coaches. Difficulties with trams are not hugely similar to those on buses (24%), trains (26%) or taxis/rideshares (8.3%). Tube/metro challenges are most similar to those on trains (58%) and buses (37%) and somewhat taxis/rideshares (14%).

From the challenges studied for our key modes of transport, we can also understand the experiences of tube/metro and coach users reasonably well, though trams are a perhaps more unique form of transport warranting further study. This suggests recommendations are relevant to wider modes of travel.

Some of the most common challenges in taxi/rideshare travel specifically include:

- The need to mask being autistic while in public (46%)
- Financial cost (46%)
- Making polite small talk (43%)
- Feeling anxious or unsafe outside the home (42%)
- Being misunderstood by others (36%)
- Unclear social rules and norms (34%)
- Not being in control (34%)
- Strangers trying to talk to them (34%)
- Struggling to travel without planning first (33%)
- Feeling trapped (30%)
- Feeling in danger (28%)
- Being nonspeaking or finding it difficult to speak while travelling (27%)
- Sensory discomfort or overload (27%)
- Feeling rushed by others (26%)

Being nonspeaking or finding it difficult to speak, making small talk and higher financial cost (expense prohibits regular usage) are challenges which are disproportionately present for taxis and rideshare travel.



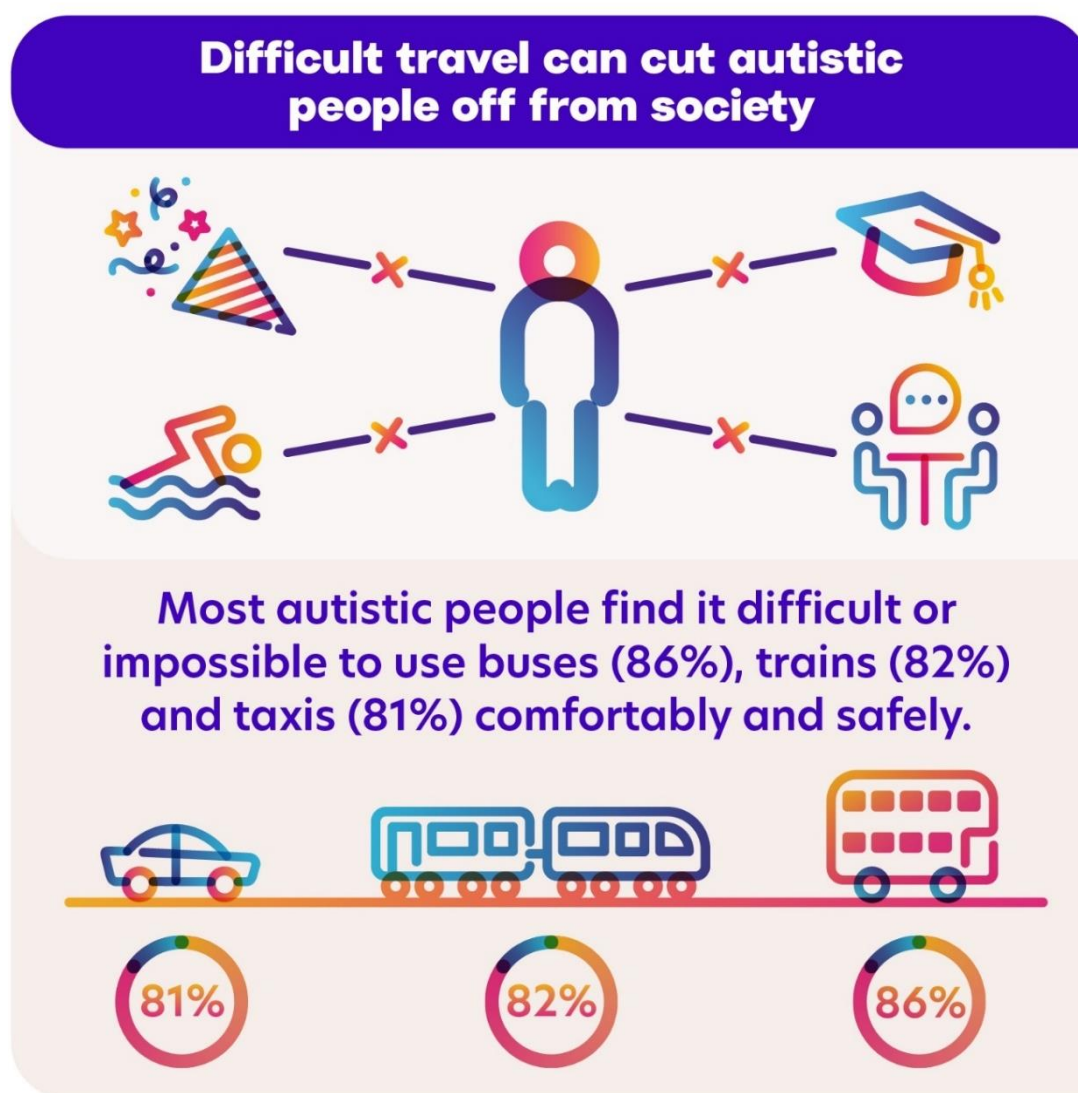
Figure 4 - The most common and impactful barriers to autistic travel



## Impact of Travel Challenges

The challenges for autistic people while travelling, can have significant and wide-reaching effect on an individual [Figure 5]. We know from the earlier snap survey that it can negatively impact the rest of their day, their access to essential services, their safety and their confidence to use transport again. Such consequences of difficult travel are important to consider.

**Figure 5 - Summary of findings on impacts of difficult travel (survey and interviews)**



We received qualitative responses on which challenges tend to have the most significant impact on autistic people feeling well and being able to finish their journey [Table 5].



**Table 5 - The most impactful travel challenges on autistic people**

| Impactful challenges                                                                                                                                                                                                                     | How they create negative impact                                                                                                                                                                                                                                                                                                                                                                                                     |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Sensory discomfort and overload                                                                                                                                                                                                          | <ul style="list-style-type: none"> <li>• Inability to cope</li> <li>• Overload and meltdowns</li> <li>• Miss important information such as audio announcements, through use of noise cancelling headphones.</li> </ul>                                                                                                                                                                                                              |
| Crowding and having other people sat or stood close to them                                                                                                                                                                              | <ul style="list-style-type: none"> <li>• Creates a difficult and stressful environment</li> <li>• Their personal bubble may be compromised</li> <li>• Exposure to challenging stimuli like strong perfumes, loud conversation and unwanted physical contact.</li> </ul>                                                                                                                                                             |
| Feeling anxious or unsafe outside the home or in public                                                                                                                                                                                  | <ul style="list-style-type: none"> <li>• May prevent travel or stop them from completing their journey <ul style="list-style-type: none"> <li>◦ Sometimes caused by previously or regularly experiencing discrimination, meltdown and lack of support during travel.</li> </ul> </li> </ul>                                                                                                                                         |
| Lack of ample seating on trains and buses                                                                                                                                                                                                | <ul style="list-style-type: none"> <li>• May lack confidence to request accessible seating for fear of discrimination or judgement</li> <li>• May experience vestibular balance issues, and struggle to stand on moving transport with ease</li> <li>• May have more sensory overload when standing</li> <li>• May experience pain or be unable to stand due to a co-occurring condition.</li> </ul>                                |
| Unexpected delays and cancellations                                                                                                                                                                                                      | <ul style="list-style-type: none"> <li>• May make other challenges more severe so they may find it more difficult to: <ul style="list-style-type: none"> <li>◦ quickly adapt to changed routines and expectations,</li> <li>◦ get the information they need to make revised plans,</li> <li>◦ navigate and understand how to find alternative routes or platforms,</li> <li>◦ make decisions under pressure.</li> </ul> </li> </ul> |
| <b>Other:</b> Needing someone with them to travel, having to talk to others, being discriminated against by passengers and staff, lack of accessible information, pressure to mask and being unable to move freely or leave mid-journey. |                                                                                                                                                                                                                                                                                                                                                                                                                                     |

Though some of these challenges such as delays and cancellations are experienced by everyone who uses transport, the impact can be much more severe for autistic people. For example, some autistic people told us about times they had to be collected by car because they could not cope with the added pressure of changed plans, couldn't manage the new journey type or route, or were stranded somewhere unfamiliar.





Others talked of on-board delays where lack of information caused them to feel trapped and experience meltdown.

*"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/carer of an autistic man who is aged 25,  
White and lives in a suburban area in the North West*

## Ideas for Change

Environmental and sensory adjustments:

- providing greater space, and broader separation;
- greater accessibility and comfort (including temperature control, air circulation);
- more comfortable, physically separated seating;
- more toilets, ramps and lifts;
- greater cleanliness;
- dedicated reduced sensory areas in both transport waiting areas and on transport itself;
- support from sensory aids such as noise cancelling headphones.

Enhanced travel and journey planning support:

- efficient and accessible travel planning and live information resources (including digital applications);
- staff available to support autistic people;
- reducing the cost for family or carer travel.

Clear and accessible information:

- information which is:
  - clear and concise;
  - timely, accurate and up to date;
- one universal, digital resource;
- simple fare structures, ticket types and payment methods;
- clearly marked safe spaces across transport facilities;
- service status and capacity information.



Managing social interactions:

- reduced social interaction (including when buying tickets, conversing with taxi drivers, ticket inspectors and asking for help);
- not being made to feel rushed;
- alternatives to include purchasing tickets remotely, or via ticket machine.

Autism awareness and understanding:

- greater awareness of the challenges autistic people face when travelling, from both the public and also transport staff;
  - including recognition of visible cues that someone might need support such as the sunflower lanyard.

#### 4.3.4 What further analysis could tell us

As well as statistical and qualitative analysis of the survey, we chose to conduct a cluster analysis including quantitative data on demographics, travel use and challenges. Cluster analysis or segmentation is a statistical behaviour analysis technique which compares and segments participants' datapoints based on pattern frequency, behavioural tendencies and common experiences, rather than pre-set demographic factors alone. In other words, this analysis can reveal different profiles of autistic transport users, differentiated by the different ways they tend to experience public transport.

Our analysis revealed three data clusters or types of autistic transport user. We intend to further analyse these clusters and report at a later date.

### 4.4 Travel User Interviews

#### 4.4.1 What we did

We conducted 20 semi-structured interviews to explore the challenges and impacts of difficult travel in more detail. On the advice of the CDG, we included not just autistic people but also some of their parents, as it was felt that this would more likely represent those who are unable to take part in research themselves and their inclusion would ensure valuable experiences were captured.



The interviews were held via Microsoft Teams or telephone at participants' request for a duration of approximately 40-50 minutes. The 1-1 format enabled interviewees to attend with a carer or peer, if preferred, to help facilitate communication. We offered each participant a £50 shopping voucher as thanks.

Interview recordings were transcribed and anonymised. Significant quotes were captured from those who consented for them to be used to illustrate their points. The interview data was thematically analysed to draw out insights from the discussions using the approach of [Attride-Stirling \(2001\)](#).

We recruited participants to interview via the initial recruitment form; sign-ups in the scoping and insight surveys; and people who got in touch via email with accessibility enquiries. On the recommendation of the CDG we included 4 parents and carers of autistic people, 4 self-identifying autistic people and 12 with a diagnosis. As with the surveys, first and second person accounts were combined in analysis.

We were able to select participants based on their demographic and access requirements, from our contact list of interested parties. We ensured a mix of rurality, ethnicities, age, genders, regions and autistic people who indicated intermittent speaking ability or use of carers. After categorising our audience, we anonymised options and randomly selected participants to ensure fairness and reduce bias.

The autistic people in this sample were aged 18-56 and 65% were aged under 35 years. There were 12 women and 3 non-binary autistic people. Autistic people of the global majority and mixed ethnicities made up 55% of the sample. We included 2 participants from Scotland, 2 from Wales and 16 from various regions across England.

#### 4.4.2 How we analysed

To analyse the transcribed interviews, we followed the [Attride-Stirling's \(2001\)](#) six-step approach to analysing qualitative data in order to generate thematic networks. This was an appropriate way of exploring the data and reducing or breaking down the transcribed material.

The information was coded by key issues that arose from the interviews. Data was segmented, and these codes applied. The identified themes generated from the coded text were refined to become *basic themes*. These were grouped into broader *organising themes*, which were then summarised into *global themes*. (See [Appendix 4](#) for the tables of the themes and [Appendix 5](#) for an example visual representation of the themes.)



### 4.4.3 What the interview data told us

The qualitative information from the interviews provided data on:

- the challenges faced by autistic people when they travel on buses, trains or taxis;
- the impact travel challenges have on the lives of autistic people;
- how autistic people try to reduce the challenges;
- potential solutions to those challenges.

## Challenges and Impact

### Environment

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

*"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.*

### Communication and interaction

- Needing, or being expected, to communicate in a certain way can be a barrier when travelling.
- Often a different way of communicating requires more processing time, or different methods to be used in order to engage.
- Needing to interact to buy tickets, ask for help, engage in conversation or respond to informal 'chit chat' increases social unease due to the pressure to communicate;
- When already overwhelmed by the environment it can be harder to communicate, especially when combined with the worry of social rejection, the fear of conflict or being confused by social expectation and social rules
  - This can all then lead to social shutdown.



*“There are so many different rules about what you're supposed to be doing on a bus and what you're not supposed to be doing and where you're supposed to sit and whether you're supposed to give your seat up.”*

*Autistic woman, aged 36,  
Black African and White, living in a suburban area of Wales.*

### Uncertainty

- It can be challenging and overwhelming to deal with change (such as delays or cancellations), and to travel when there is uncertainty about how it will happen.
  - This can cause anxiety, discomfort, fatigue and catastrophising.

*“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.*

### Public judgement and discrimination

- Autistic people and their families told us that their journeys are impacted by other passengers.
- They emphasised that autism is often not easy to accommodate, and people don't know that sometimes changes are needed to support autistic people.
- Others may not realise or believe someone is autistic.
- Some autistic people felt that there is a lack of public empathy which comes from not understanding the challenges that autistic people face.
- Many autistic people feel judged by non-autistic people especially if they experience overwhelm that leads to panic or meltdowns in public.
- This all impacts autistic peoples' confidence to travel.
- Some autistic people are exhausted by travel situations due to the expectations of other people.



- Often autistic people feel that they must hide their usual responses or 'way of being' to fit in with expectations and so they 'mask' or hide their autistic characteristics.
- We heard from some autistic people who have faced abuse and explicit discrimination when using transport which has a lasting impact on their confidence to travel alone again.
- They sometimes face challenges from staff and the public who misunderstand their distress as aggression.
- There was a point of view that if the public and transport professionals knew what autism is and why autistic people face challenges then there would be greater understanding, more acceptance of difference and an improved attitude, enabling autistic people to 'be themselves' and openly use their coping strategies while travelling.

*"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,  
living in an urban area of London.*

### Lack of clear, accessible information

- Successful journeys and having the confidence to travel was impacted by the lack of clear, accurate and accessible travel information.
- In busy places when there is a lot of information to process, this is made harder by sensory distractions and overwhelm.
- Many autistic people may be unable to approach staff with questions due to overwhelm, social anxiety or being nonspeaking, so alternative formats are essential to help them access information.

### Impact on wellbeing

- Facing challenges when travelling can impact an autistic person's mental wellbeing and contribute to a loss of confidence and independence.
- Due to all the challenges discussed above, autistic people are more likely to experience high levels of anxiety, stress and exhaustion.
- These high emotional levels can lead to emotional dysregulation and prevent them from travelling, potentially making some autistic people feel a sense of failure.



*“It can take you a lot of time once you get home to recover from all of that. But then if you've got things to do once you get home, then it just has a knock-on effect and it just ends up with you being in this energy debt from having to get home.”*

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

## Strategies to Reduce Challenges

### Reducing sensory overwhelm:

- headphones and noise cancelling items;
- regulatory items, fidget toys, puzzles, food, drink and distractions (a reading book);

### Reducing uncertainty:

- accessing live trackers to know exactly what is happening in real time;
- emotionally preparing for a journey by actively taking time to relax before, and reflect and recover after;
- practising journeys to increase familiarity and reduce unpredictability;
- using quieter travel times where this is possible;
- choosing a mode that provides greatest control;
- planning strategies to manage not being in control;

‘Solutions’ proposed by autistic people are discussed in more detail in [Appendix 4](#) and the recommendations section of this report.

## 4.5 Transport Professional Focus Groups

### 4.5.1 What we did

Initial findings from the survey, and insight from our CDG, informed a discussion guide to use as a structure for focus groups with transport professionals.

There were two focus groups, the first with four participants and the second with six. Both groups were conducted virtually using Microsoft Teams, and each was 2 hours in length. Participants were offered a £50 ‘thank you’ voucher.





Participants were recruited by advertising via social media, email newsletters, and existing networks.

Unfortunately, social media attracted expressions of interest from many non-genuine enquirers, which gave us a false impression of level of potential participants, and was time-consuming to filter out. We later took a different approach to populate our solution testing workshops.



Attendees received an information sheet in advance, outlining the broad topics of discussion, how the information they shared would be used and stored, and prompting choices around level of permission for quotation use. Attendees were sent an agenda and slides in advance, and one individual requested a pre-meeting as well as sample questions which was accommodated.

The group were presented with broad findings from surveys and interviews to date – highlighting the key challenges that impact autistic people’s wellbeing and ability to travel. They were also presented with three personal stories written by some of our CDG.

These real-life experiences illustrated some common barriers to travel and the impact this can have, and were prompts for useful discussion. The focus groups were recorded, and the discussions later summarised.

#### **4.5.2 Who we spoke to**

Participants included a council transport planner, travel trainers, researchers of transport and accessibility, accessibility leads within transport providers (bus and rail), and a service staff member (trains). Many of these transport professional representatives were autistic or had a close family member or partner who was autistic.

During the focus groups with transport professionals there was discussion about transport professionals’:

- knowledge of autism and perceptions of autistic people’s experiences of travel;
- current support offer, appetite for improvements and limitations.



### 4.5.3 What we found

Discussions concluded that there is currently:

- a wide range of autism or wider disability training available to transport professionals, and there was concern regarding the quality or consistency of the training provided;
- variance in autism understanding amongst transport professionals, which is hard to manage;
- no set guidance on autism compared to other disabilities or needs;
- an appetite for change but this depends on location and travel company;
- a discrepancy between bus and rail services with rail services being more advanced in what they offer to autistic people;
- conflicting priorities for transport professionals;
- a feeling of not knowing where to start or how to address the challenges;
- financial constraints;
- the need to fill every seat and make money;
- useful support available but it is not well-known or communicated.

Examples of current support offered to autistic people mentioned in focus groups included:

- having autistic colleague networks and groups;
- schemes like cheaper travel (including for carers);
- passenger assistance (although this varies);
- awareness cards that can be carried;
- travel mentoring and trialling.

There are, however, limitations to what can be offered:

- strategies need to consider conflicting needs of passengers (e.g. a partially sighted passenger might rely on audible announcements which might cause overload for others);
- there are legal requirements to consider (e.g. level of lighting on a bus).

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

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

They also suggested:

- autistic people should input on and evaluate changes;
- VR for planning and walk-throughs could be useful;
- autistic needs should be embedded in designs and plans;
- financial cases can demonstrate that strategies will help all.

These discussions provided valuable insight and informed subsequent solution testing workshops.



## 4.6 Solution Testing Workshops

### 4.6.1 Who we spoke to

Participants at the solution building workshops included accessibility, diversity and inclusion officers from a number of train and bus operators and membership organisations. In addition, there was participation from local authority travel planning officers, travel training providers and consultants. These workshops were facilitated to enable us to test the applicability of the co-created solutions.

A total of 19 professionals attended our workshops. There were three sessions and each lasted between 1.5 to 2 hours. Again, all participants were offered £50 vouchers. Some participants had been involved in earlier stages of our research. Most we recruited via a convenience sample by contacting transport providers and directly asking for a contact in their 'accessibility teams'. This recruitment method resulted in attendees from many rail and underground networks. We limited attendance to no more than one representative from each provider or organisation in order to draw a sample from as broad a range as possible.

### 4.6.2 What we did

Attendees were given an information sheet outlining the purpose and format, and were prompted to choose a level of permission and anonymity for quote usage. A brief agenda was also shared in advance. Sessions were recorded, and summarised.

At each workshop 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).

The SFA testing model of evaluating proposed solutions is useful to ensure that what is being suggested is not an out-of-reach ideal but a solution that can be presently applied to affect change. The workshops were also an opportunity to establish transport providers buy-in to the final recommendations and to discuss useful outputs from a transport professional's perspective.

*"We'd like a guidance document, like a short 10-page thing that covers the different things, because there's not just one kind of autistic person."*

*Strategic Transport Planner for a City Council, England.*



At the solution building workshops, travel professionals were asked to consider user ideas based on three criteria:

- *suitability* for both the operator's workforce and customer base;
- *feasibility* within statutory requirements and resource limits;
- *acceptability* in line with broader operator policy and industry standards.

The ideas for change, or the solutions were grouped into the following categories:

- environment and space including sensory adjustments;
- journey planning;
- travel support;
- social interaction.

#### 4.6.3 What we found

The workshops highlighted that the transport industry already uses many initiatives to enhance travel experiences for autistic people, and that there was a keenness to further address barriers and challenges autistic people experience during travel.

##### Environment and space including sensory adjustments:

- Physical alteration of transport vehicles, stations, terminals or waiting spaces are restricted by statutory, practical and resource limitations.
- Current policy dictates maximisation of passengers (rather than the creation of more space).
- Similar limitations apply to sensory adjustments, for example, train design limits ventilation options or the ability to open windows on certain train types.
- There may be some practical workarounds to afford individual space such as single flip down seats in train vestibules.
- Waiting spaces that cater for sensory sensitivities are a feasible solution, especially in stations that have sufficient physical capacity to accommodate them, and such spaces exist in some stations already.
- Duplicating these spaces to more stations relies on suitable space being available and building regulations and planning permissions being possible.

*"It feels tough to teach young people coping mechanisms rather than them getting the service they deserve from public transport."*

*Travel Trainer for a travel training programme, England.*



### Journey planning:

- Many of the solutions relating to journey planning may already exist but they are difficult to find, not always clear and sometimes lack accessibility;
- Some stations are already adopting 'street views' and walkthroughs to offer a closer view of the station and help prepare travellers for what to expect.
- Whilst many commercial journey-planning digital applications were comprehensive, they do not draw their data from official sources which impacts accuracy.
- New accessible journey information systems are being tested or put into operation including the use of QR codes on trains providing live information.

*"It goes beyond a tick box exercise. With public transport, there are so many people diagnosed or undiagnosed who are neurodivergent. It's a really good place to start with disability awareness since it benefits everyone."*

*Accessibility and Inclusion Officer for a bus operator, Scotland.*

### Travel support:

- The cost implications of taking a carer or support person on a journey to accompany an autistic person were discussed.
  - The disabled railcard scheme already allows for discounted travel for a support companion, however broader reductions or any current issues with the existing railcard scheme were deemed outside of transport provider scope.
- It was noted that one train operator has been through an autism friendly accreditation process, but that further collaboration between the National Autistic Society and operators could be explored.
- Some operators run travel mentor or support schemes, though there are budget restrictions.
- Some felt that official support cards or identifiers could be useful, for example to indicate someone with a hidden disability may need a seat.

*"[The problem is] treating passengers as cargo with pure consideration for speed and time, rather than thinking about the whole journey door-to-door."*

*Strategic Transport Planner for a City Council, England.*



### **Social interaction:**

- Some providers showed commitment to maintaining manned ticket offices supplementary to online and automated ticket purchasing options.
- Further training (to ensure transport staff understand the challenges autistic people face when travelling) was seen as a positive step.
- Some of the mitigations for minimisation or management of social interactions during travel would require shifts in public understanding and awareness.

These discussions were valuable in helping us to refine our recommendations.

## **4.7 Outputs Survey**

### **4.7.1 What we did**

The purpose of this second short-scale survey was to get a snapshot of how autistic people would like to hear about the findings of the project. We used the survey to gauge which resource formats would be most interesting, accessible and usable for the audience. This method of engagement added another layer of scrutiny to ensure we were centring autistic people. The findings from this survey were then reinforced by the CDG and discussed with transport professionals.

### **4.7.2 Sample**

We heard from 117 autistic people (88% diagnoses), and those close to them. The majority were autistic people, women (60.7%) and working-age adults of 20-39 years old (40%) or 40-59 years (35%). Nearly 15% of respondents were also non-binary.

As we had a small sample size, we used this data as a rough guide for our activity and also consulted heavily with the CDG to verify the suggestions and make decisions about the direction of our outputs. We also (on the CDG's suggestion) briefly discussed outputs with transport professionals during workshops, to find out what information, and format types, would be useful to them.

### **4.7.3 What we found**

Survey findings and subsequent discussions have shaped our outputs/resources plan to include updated web content, infographics, visuals and video content, research articles, short summaries and case studies. Our insight and findings will be converted into essential resources for the autistic community, and transport industry.



## 5 Discussion

### 5.1 Addressing the Research Question:

Our research question refined by autistic people asked:

*How can we address the most significant challenges experienced by autistic adults using trains, buses, taxis and similar forms of transport in the UK?*

Our research first told us what those challenges are, and what impact they have. Next, we explored what autistic people find helpful when travelling, and what more they think could be done to reduce barriers. Finally, we consulted with transport professionals to refine solutions into feasible and sustainable recommendations for transport providers, autistic transport users, families, friends, and the general public.

We have reached a number of recommendations for each stakeholder, addressing challenges relating to the environment, information/planning, interaction, support provision, and general autism understanding. These range from tips autistic people can adopt to systemic changes in the way autism-friendly travel is considered and prioritised across UK travel networks.

### 5.2 Findings in Relation to Existing Literature:

Whilst there was limited research on this topic, our findings are in line with existing literature. [Rezae et. al., 2021](#) and [McMeekin et. al., 2020](#) identified anxiety around navigating travel and unexpected change, sensory sensitivities, and communication differences as some challenges that autistic people face. Travel solutions including improved information, training for professionals, and less overwhelming sensory environments are also reflected in existing literature [Dirix et. al. \(2023\)](#).

### 5.3 Findings in Relation to Theories:

Our findings are consistent with current understanding of autism and its core characteristics, with our findings evidencing differences in communication and interaction, preference for predictability, and sensory differences being key contributors to travel challenges. The findings also evidenced what we know about societal lack of understanding, judgement, and environmental factors all impacting autistic people's experiences of navigating everyday life. Many autistic people have





high levels of anxiety, and are either exhausted by or entirely miss out on social, education and employment opportunities.

Our findings demonstrate the impact of travel on aspects of life which non-autistic people might take for granted. We have also evidenced that many autistic people have co-occurring health or neurodevelopmental conditions, or other intersecting identities, which can also increase barriers to travel.

## **5.4 Findings in Relation to Practice:**

Transport providers have competing priorities, policies and legislations to adhere to, all within restrictions of budgets and infrastructure. Our findings will give transport providers the evidence to justify change as well as considering 'next best' options where solutions cannot be immediate. We know that even small changes can go a long way, and the project has highlighted a number of good initiatives.

We have also discovered that transport providers are already keen to further support autistic people through travel and schemes and support, which are already in place or being considered in many cases.

We know that many of the changes autistic people want to see are possible, either directly or through a series of workarounds. The recommendations in this report shape the landscape for transport providers to ensure their particular modes of transport are as autism friendly as possible.

## **5.5 Why This Is Significant:**

This research is the first of its kind, addressing a significant gap in evidence, capturing so many autistic people's experiences, and being truly autistic-led in its delivery. It has the potential to influence real positive change.



## 6 Recommendations

Using the multiple methods of data collection (including surveys, interviews, focus groups, workshops, and CDG discussions) all qualitative information was thematically analysed to develop basic themes. This means the responses were coded and grouped into common themes to understand trends in the data. We then 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 from all the participants at every stage of the data collection process.

Note, much of our commentary around recommendations refers to train and bus travel, as we gained the most insight on these ways of travelling. Though we gained a good understanding of challenges with taxi travel, for example, professional engagement from this audience was low, meaning we do not have a good understanding of how applicable user suggestions may be in practice. We know, however, that many challenging experiences are felt regardless of transport mode and therefore many recommendations here can be adopted across the industry.

There were five themes of recommendations that emerged from the data, the need for:

- support for autistic travellers;
- accessible information;
- sensory adaptations;
- autism understanding;
- reducing uncertainty.

Each of these themes generated recommendations which will each have implications for autistic people, their families or friends, transport providers and the general public. These recommendations reflect insight from autistic people accessing different modes of travel and different providers of transport, UK wide. This means some suggestions may already exist in some settings but not others. Currently, travel experiences range from 'excellent practice' to 'needing significant improvement'.



## 6.1 Travel Support

Often autistic passengers don't know what support may already be available, especially as it can differ between providers and regionally. We know that some autistic people feel very reliant on support from family, carers to be able to travel. However, this is not always possible, and reliance on others to can limit independence.

Many autistic people told us that if they knew that there were **dedicated transport professionals** available to support them then this could:

- reduce anxiety and stress levels;
- reduce feelings of guilt or shame from asking for help;
- increase likelihood of completing a journey;
- Increase certainty about what to do when there are delays, cancellations and changes;
- increase independence and confidence;
- reduce fear of negative feedback such as discrimination or bullying;
- reduce fatigue, exhaustion and burnout;
- allow for time to process and ask questions without being rushed;
- help to manage meltdowns in public without fear of stigma;
- help to find out what support is already available in stations and services.

Autistic people would like assistance to be easy-to-arrange, including support at travel facilities, like train and bus stations and onboard vehicles. This could be facilitated via a recognised autism support scheme, with dedicated professionals having additional training to understand the differences and needs of autistic passengers.

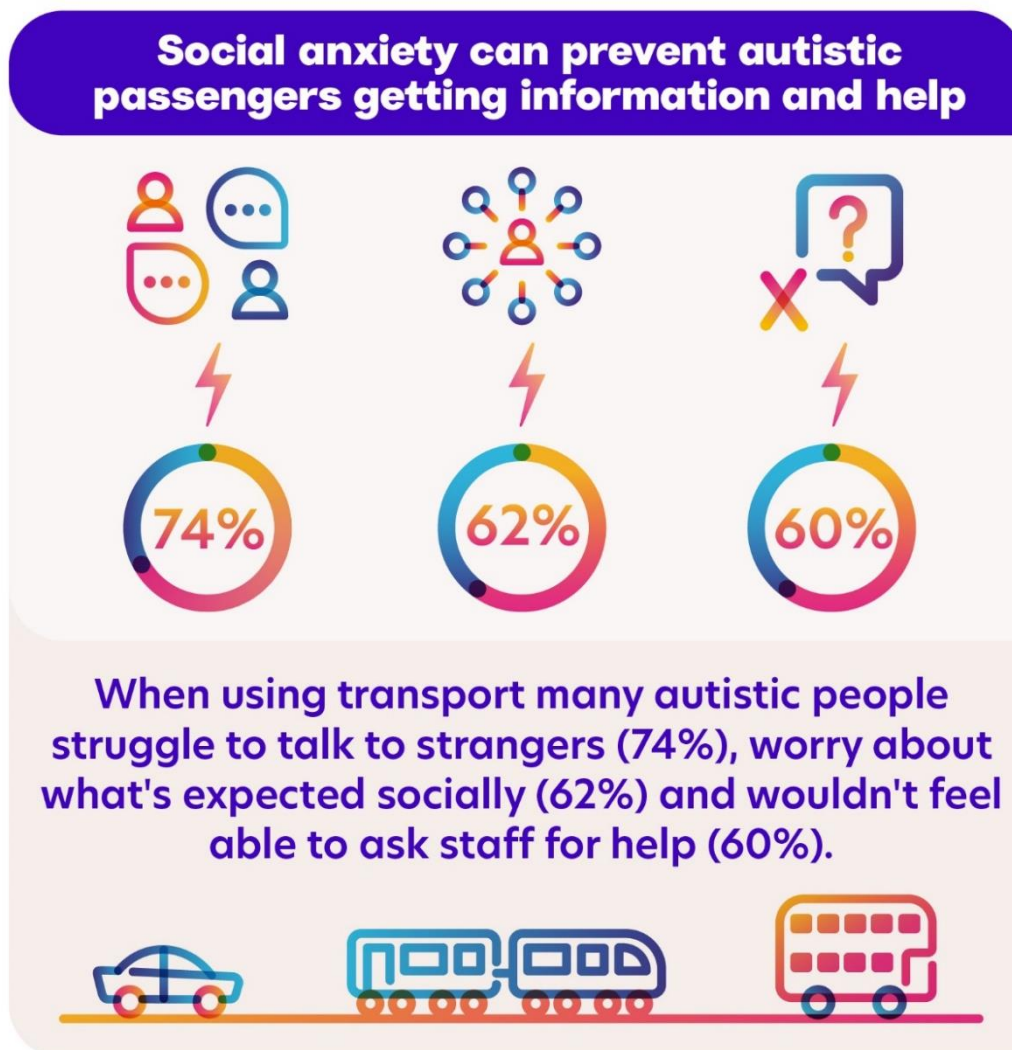
Support staff being clearly identifiable is important as it can be intimidating approaching someone for help [Figure 6]. **Ensuring good availability, flexibility and reliability of assisted travel is essential** for providing better support to autistic users.

*"The expectation is that you have to tell other people how you need to be accommodated, which is really difficult sometimes when you don't know."*

*Autistic woman, aged 36,  
Black African and White, living in a suburban area of Wales.*



Figure 6 – Summary of findings on social difficulties during travel (survey and interviews)



It is worth noting that not all autistic people will be able to approach staff for support or use assisted travel services, even with these 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. Some might not be able to rely on verbal communication.

For such passengers, travel support could:

- support the use of sensory regulation tools such as ear defenders, capped hats, fans;
- have communication cards for passengers to let staff know their need.
  - appreciating that some passengers prefer not to display their difference publicly with, for example, a sunflower lanyard.



*"I want it made clear that the providers of the transport need more training, because it's not just a wheelchair and a ramp."*

*Autistic woman, aged 32, White, living in a rural area of Scotland.*

A supportive transport professional can offer:

- sympathy and support if recovery time is required (without rushing the individual);
- 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;
- patience and support for those who are nonspeaking or find it difficult to speak whilst travelling;
- options to get information and help without talking;
- assistance and benefit of the doubt if an autistic person travels with an incorrect ticket type;
- reassurance.

*"The train guard was absolutely brilliant in a situation where he felt incredibly panicked. He was very calmly checking in with him, explaining exactly what had happened and saying 'I'm going to find out more information, then I'm going to come back to you, it might be a few minutes. Do you have a drink, would you like something?' It was just outstanding, it was textbook perfect the way he was managing the situation. Having somebody on public transport that can understand and manage those sorts of things makes a huge amount of difference."*

*Parent/carer of an autistic man who is aged 20, White and lives in a rural area in the South East.*

Transport providers could also:

- consider clearly promoting existing support mechanisms and resources;
- produce clear information in one place on their websites to explain what support is available for autistic passengers and how to access it;
- consider how they can make support points clear in public spaces so autistic users know who to approach for trusted, trained support;



- consider autism friendly accreditation schemes or similar;
- work with travel training scheme providers
- offer discounted rates on accompanying carer tickets where possible.

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.

## 6.2 Accessible Information

Travel information can be difficult to process when it is not clear or accurate, compounded by busy environments with sensory distractions. As above, many autistic people may also be unable to approach staff, so alternative formats are essential to help them access information.

Autistic passengers suggested they would greatly benefit from:

- 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, etc;
- clearer signposting at stations, particularly towards the nearest exit (when the priority is exiting quickly), or particular exits;
- clear visible floor markings, colour coding, and clearly marked spaces (which do not compromise other passengers' needs);
- improved visual maps;
- information across multiple services combined into a single official source wherever possible,
- changes to timetables and routes including seasonal changes announced in advance;
- reasons for delays and cancellations explained clearly wherever possible;
- clear visual instructions on how to use ticket machines and barriers or someone to ask, including simplifying ticket selection.

In order to travel successfully, passengers need **easy access to information** about their potential journeys. They tell us that often it is difficult to find the information they need in advance and while travelling and it would help greatly if:

- travel information could be presented in accessible formats including easy-read information;
- timetables were presented in an easier format;





- contact details for station services and travel enquiries are accessible so people can ask for more information if needed;
- ticket buying processes and ticket selection was clear and accessible;
- virtual walk-throughs were more widely available and better advertised.

Having information available before travelling is important for autistic people to anticipate what may happen, help with navigation and reduce anxiety before travel.

*"The apps can be very confusing with the different types of ticket. He doesn't want to buy the wrong ticket, he'd be mortified, but that confusion then leads to distress."*

*Parent/carer of an autistic man who is aged 25,  
White and lives in a suburban area in the North West.*

Although there are apps that can be downloaded onto digital devices these are not available for all transport types and are not always easy to navigate. Autistic people would welcome apps that:

- are simplified or specific for those who communicate differently (some currently in development);
- provide advanced information about planned changes, and live information e.g. delay times that are accurate, reliable and consistent;
- allow online booking and ticket purchases for all transport types.

(It is acknowledged that there are reliability issues with some third-party information apps at present especially when considering journeys split across different modes of transport.)

*"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/carer of an autistic man who is aged 20,  
White and lives in a rural area in the South East.*





## 6.3 Sensory Adaptations

Journeys and travel plans are made much more difficult due to the sensory differences [Figure 7]. 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 some passengers to process information such as announcements, and can trigger meltdowns or make autistic people feel very unsafe.

With some **environmental adjustments** it could be possible to make these intense sensory environments more accessible to autistic people. They told us that it would help if:

- there could be quiet/safe spaces provided at stations alongside public awareness information to explain their purpose;
- trains had a pre-bookable quiet carriage or adapted carriages that consider wider sensory overwhelm (lighting, textures);
- vehicles could be kept at a comfortable temperature;
- bus services could continue investment in electric vehicles for quiet travel;
- stations or waiting areas could be designed to be less visually and audibly overwhelming;
- vehicles are well maintained and regularly cleaned, with the ability to report problems easily;
- there was individual seating on transport, or a way of better maintaining personal space whilst seated;
- they were able to take a break in their journey on the same ticket.

(It is acknowledged that there are a number of logistical and financial barriers to creating extra space, though there are some potential workarounds.)

In addition to consideration of the recommendations above transport providers could:

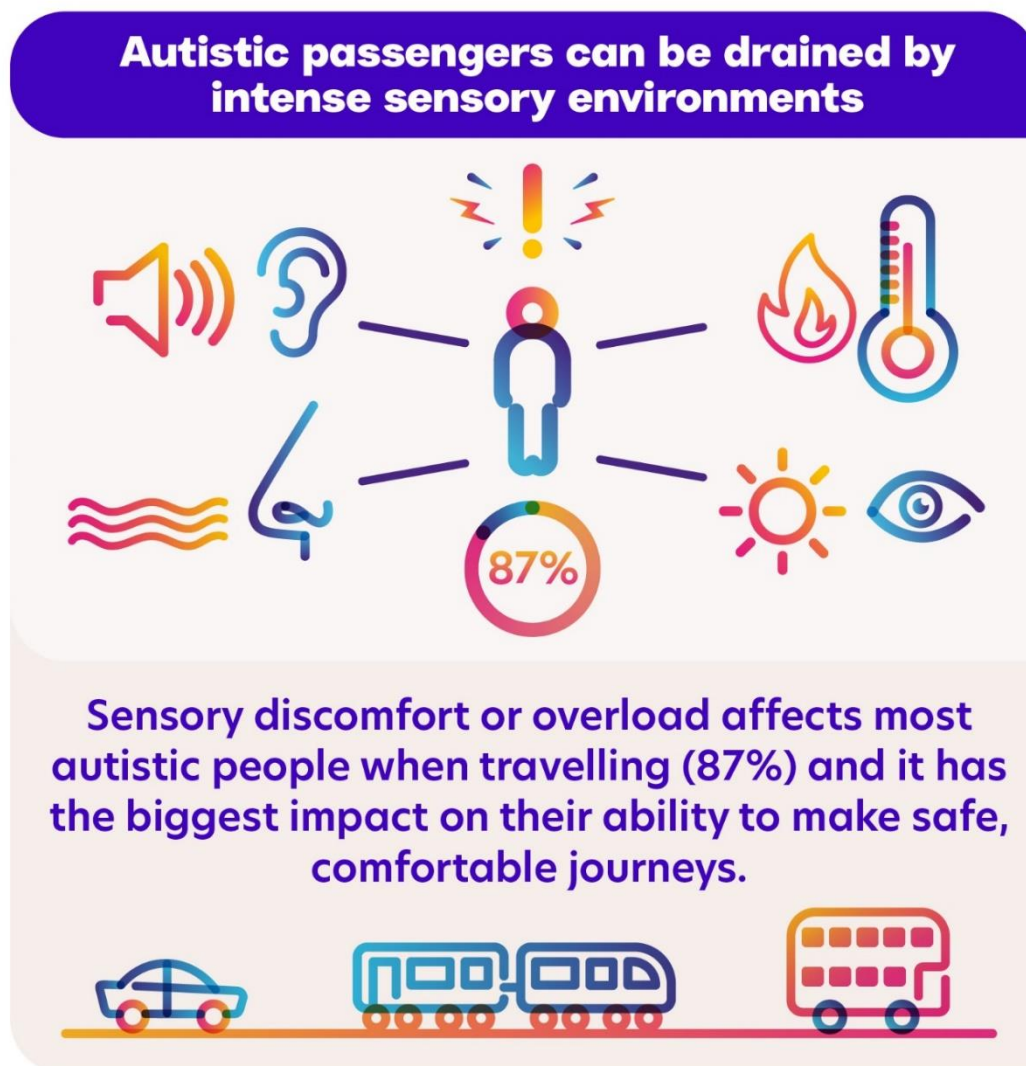
- clearly communicate the barriers and limitations to adoption of recommendations;
- consider inclusion of autistic people in the future design of transport and waiting spaces;
- consider 'next-best' alternatives to space and sensory accommodations.

Autistic people could also use:

- headphones and noise cancelling items;
- regulatory comfort items (such as fidget tools, puzzles, or food);
- controlled distraction by engaging in a pleasurable activity, for example, reading.



Figure 7 – Summary of findings on sensory difficulties during travel (survey and interviews)



## 6.4 Autism Understanding

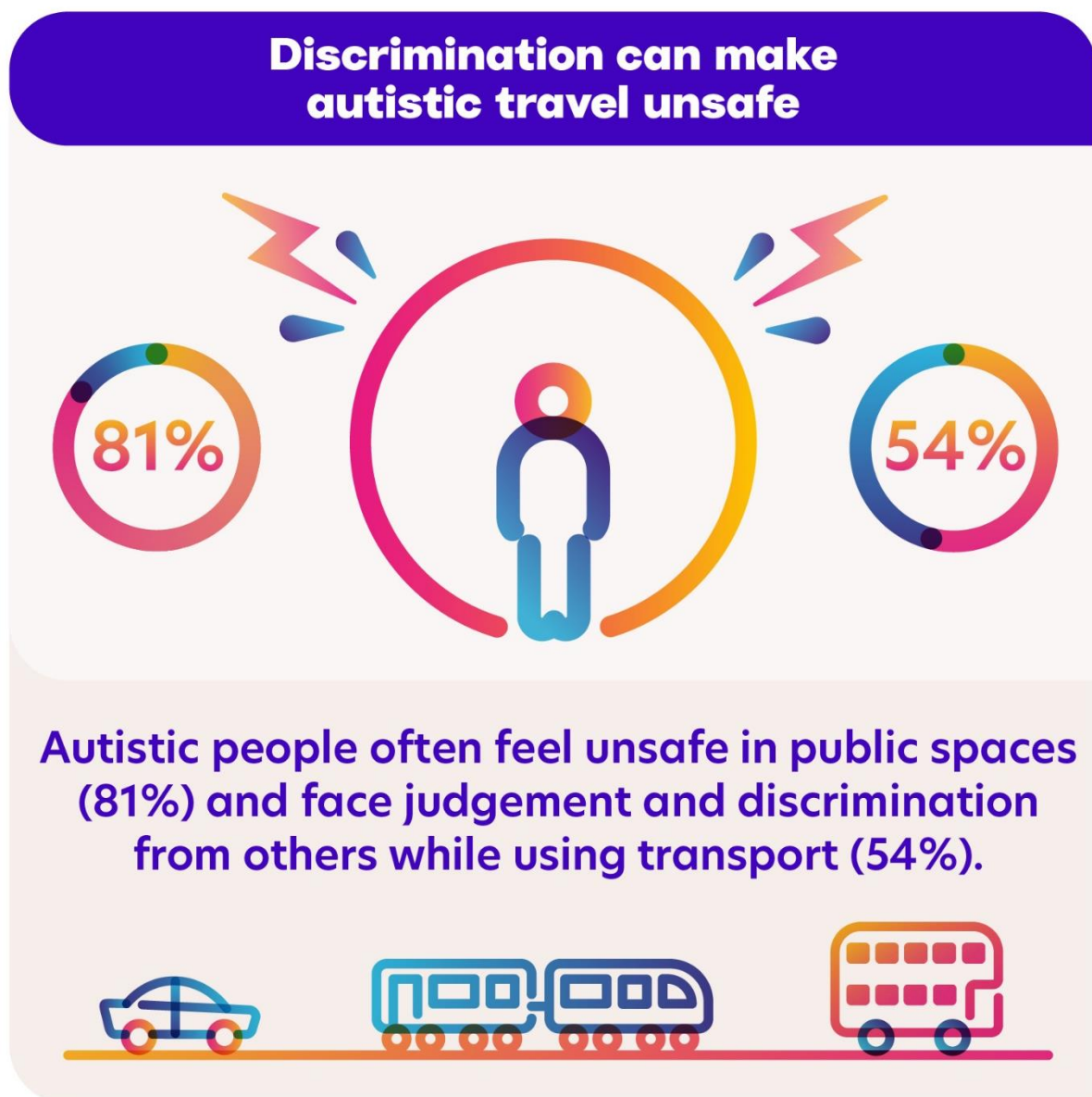
Autistic participants felt that there is a lack of public empathy which comes from not understanding the challenges that autistic people face.

We heard from some autistic people who have faced abuse and explicit discrimination when using transport which has a lasting impact on their confidence to travel alone again [Figure 8].

*"I often don't have the 'spoons' to fight with them and advocate for myself in a stressful situation because there is still such a lack of knowledge and understanding and empathy, particularly around hidden disabilities, like why people might need to use accessible toilets, for example."*

*Autistic woman, aged 19, White, living in the East Midlands.*

Figure 8 – Summary of findings on discrimination during travel (survey and interviews)



Sharing information about autism and travel with the public would go some way to address the challenges that participants tell us that they face. Travel would be more successful if there was **public understanding and recognition** of:

- autism;
- social and communication differences including;
  - social situations can be uncomfortable and unwanted;
  - some need extra time to process questions;
  - some are non-speaking and need to communicate in alternative ways;
- autistic meltdowns;
- sensory overload;
- stimming and self-soothing behaviours;
- accommodations that can be made by them;

Autistic people and their families told us that informing the public about autism and how to support them in transport settings will help reduce the:

- pressure to communicate;
- fear of social rejection;
- need to mask to avoid being perceived as 'odd';
- apprehension about disclosing their autism;
- need to manage situations to avoid talking;
- fear of feeling unsafe outside the home or in public;
- likelihood of being misunderstood by others;
- feeling of being in danger;
- judgement or discrimination by others.

Autistic people believe being informed should help the public to:

- be empathetic;
- recognise autism;
- accept difference.

Many of those who we talked to felt that the following would make a big difference to their confidence and capability to travel. If transport staff could:

- receive autism training;
- allocate a named autism champion in their staff team who advocates for autistic users;
- receive case studies or real stories that bring the travel experiences to life;
- invite and join autistic passengers on a ride-along journey to better understand the travel experiences autistic users face;
- work with autistic consultants to design and evaluate any initiatives;
- access autism friendly award or accreditation schemes for their teams and locations.



*"I think definitely part of the training should be to listen to stories and experiences of those that are autistic and disabled so they can see us more as people and humanise us by putting a face to and these to these stories."*

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

It is also important for professionals to **offer support or ask what someone needs** even if they're not sure if they're autistic. Professionals should be trained to understand that there's 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. In addition, many autistic people have co-occurring conditions which further impact their need for support.

The best way to inform the public would be:

- to disseminate and share research and recommendations;
- to publish digital advice and guidance across both autism charity and transport provider websites;
- a public campaign to raise awareness of autistic people's travel needs.

In addition to the recommendations above transport providers could:

- identify needs for autism training and accreditation;
- ensure training is high quality and involves autistic people;
- support raising 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.

*"There are some really, really lovely people that I've come across on my journeys and they give me hope and faith. They've been so lovely, so accommodating and good to me. It really doesn't cost very much, but it does make the world a difference to people like me. It absolutely makes my day when somebody is kind."*

*Autistic woman, aged 19, White, living in the East Midlands.*



## 6.5 Reduce Uncertainty

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*.

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 or 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;

Transport providers can:

- provide planning checklists and resources;
- communicate in advance when there will be engineering works or strike action or closures;
- clearly announce any changes or replacement plans, cancellations and delays and consider how to feed this into clear and accessible online information;
- improve the consistency between transport vehicles to reduce uncertainty from every vehicle and carriage being different;
- implement and support travel training schemes for autistic people to help with planning and testing out new journeys;
- simplify ticket schemes and purchasing options, maintaining the ability to buy tickets from a manned ticket office, automated machine and online wherever possible.





## 7 Limitations and Challenges

- A lack of professional engagement with taxi drivers has meant our understanding of how challenges can be addressed has not had the same cross-examination from professionals as with trains and buses.
- The research comprised a large self-selecting sample. Whilst the sample is large enough to be robust for the purposes of the research it is not fully generalisable to the entire autistic population, and will not reflect all experiences and needs. Within the timeframe it was not possible to carry out further demographic breakdown and analysis to identify any significant patterns based on gender, age, geographical location, ethnicity, or co-occurring conditions.
- No control group testing was carried out for comparison, e.g. capturing non-autistic people's experiences of transport and travel).
- The focus was the modes of transport flagged as most problematic and impactful – Therefore, other modes particularly relied on in rural areas like ferries or coaches were not featured.
- While we sought to hear about experiences in the devolved nations, some research stages had limited involvement from Wales, Scotland and especially Northern Ireland and due to their different policies – It would be beneficial to dedicate study to each individually, which was out of the scope of this project.
- Research was undertaken online – though telephone appointments were an option for interviews, all advertising was online, and surveys were online only, limiting our opportunities to hear from autistic people who are digitally disconnected.





## 8 Conclusions

This was a thorough and robust piece of participatory research that addressed the evidence gap on autism and transport. It has provided vital insight into autistic people's experiences of using transport and making journeys, as well as proposing 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.

Transport providers should consider our recommendations where possible, and take care to genuinely consult with autistic people and ensure inclusivity in their planning.

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

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## 9 Appendices

### 9.1 Appendix 1: Rapid Review Search Strategy

|                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Search date                              | 04/04/2024, 12/04/2024                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| Search terms                             | <p><u>Primary</u>: Autism, autistic, ASD, Asperger</p> <p><u>Secondary</u>: Transport, transportation, travel, public transport, bus, car, train, commute</p> <p>Additional: blog, experience</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| Search sources                           | DeepDyve, Google, internal resource spreadsheets                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| Scope and inclusion & exclusion criteria | <p>Research:</p> <ul style="list-style-type: none"> <li>Sources within the last 5 years – start date for search is 4/01/2019 to day of search in April 2024. Exceptions are papers gathered during original scoping review (for funding application) in Dec 2023.</li> <li>Focusing on abstract, methodology and findings. Using references to identify other relevant studies.</li> <li>Sources reviewed must be autism-specific, accessible in English and using existing journal subscriptions.</li> <li>Not research summaries (e.g. presentations), and must have sources included.</li> </ul> <p>Professional guidance:</p> <ul style="list-style-type: none"> <li>UK-specific (ideally) and created within the last 5 years.</li> <li>Autism-specific</li> <li>Original content – e.g. not just referring to other resources (resource lists)</li> </ul> <p>Lived experiences:</p> <ul style="list-style-type: none"> <li>Autism-specific</li> <li>UK-specific- (ideally) and created within the last 5 years – unless there are sources with beneficial lived experience insights.</li> <li>Related to road and train transport</li> <li>Drawn from personal experience (e.g. not drawn from other sources or summarising general information).</li> </ul> |



## 9.2 Appendix 2: Ethical Guidelines and Principles

We will ensure that we gain appropriate assent and consent. Assent, in most cases, acts as a supplement to the requirement of consent from a parent or guardian. Informed assent should involve a clear agreement to participate, rather than the absence of any objection. We will do this by ensuring that our participant information sheet (PIS) is accessible to people of all ages considering communication differences and preferences. This will be an ongoing process and the decision to participate will be checked throughout the project.

We will obtain written consent as appropriate and if any participant can't write then a mark on the document is acceptable. Young people are normally presumed to be competent to give consent to participate in research on attaining the age of 16. If we have concern about whether the person is competent to consent for the project the voluntary consent of an adult parent / guardian will be sought before they engage in research. We will ensure that our information includes GDPR and the use of any personal data in line with National Autistic Society's [privacy policy](#). All transcripts will be anonymised and all recordings stored securely and deleted once transcribed. Researchers who work directly with the young people or vulnerable adults will have enhanced Disclosure and Barring Service (DBS) clearance.

We will consider in our dissemination strategy how the participants can challenge potential misrepresentations of themselves. We will set out clear expectations at the start of the workshops, interviews and focus groups as well as in our PIS and the limitations of the research will be explained so that participants do not have their hopes raised that issues or problems discussed in an interview will be resolved. The limitations of the researcher role will be clearly explained.

We will share a clear plan of support. The facility to debrief after participation will be made available where necessary. There will be a named individual that is not connected to the project who will be accessible should anyone want to complain about the project. We will ensure there are structures to support those affected if any data has emotional content through the disclosure of distressing any aspects of their lives. We will escalate any safeguarding concerns following the processes established.

Dignity will be preserved for all involved in the project. We will make sure our project is designed to minimise any inconvenience, intrusion, embarrassment, coercion or distress. We will be sensitive to cultural issues, concerns and values that any person may hold. For example, the acknowledgement of religious fasts.

Disparity between the power and status of the researcher and the participant(s) will also be addressed within the research design. We will have a clear plan in place for how findings will be shared with those who have taken part in the research study.



### 9.3 Appendix 3: Outcomes of Co-design Group Activities

|    | Date      | Activity                      | Outcome                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|----|-----------|-------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. | June 2024 | Introduction session          | <ul style="list-style-type: none"> <li>• Agreed on a refined project scope</li> <li>• Raised some significant elements of travel to explore including: <ul style="list-style-type: none"> <li>◦ perception of danger;</li> <li>◦ reliance on social interaction (including verbal communication);</li> <li>◦ impact of intersecting identities on social interaction/judgement;</li> <li>◦ co-occurring health conditions, minority ethnicity, or gender minority;</li> <li>◦ sensory environment and crowding;</li> <li>◦ impact of cancellations.</li> </ul> </li> <li>• Noted that while study of challenges will be autism-specific in focus, many 'autism-friendly' strategies may benefit all.</li> <li>• Agreed plans for future meetings and review activities</li> </ul>                |
| 2. | June 2024 | Insight survey design session | <ul style="list-style-type: none"> <li>• Raised ideas for the insight survey topics including: <ul style="list-style-type: none"> <li>◦ strategies autistic people find helpful;</li> <li>◦ the impact of travel;</li> <li>◦ what would make travel easier and more accessible;</li> <li>◦ good or bad examples of support;</li> <li>◦ focus on stations and waiting areas, not just on board;</li> <li>◦ talking to some people who don't use public transport at all;</li> <li>◦ any differences in devolved nations.</li> </ul> </li> <li>• Suggestions on survey design, for example: <ul style="list-style-type: none"> <li>◦ plain language;</li> <li>◦ clearly share purpose of survey;</li> <li>◦ free text boxes where possible to expand on answers (optional).</li> </ul> </li> </ul> |
| 3. | June 2024 | Insight survey review         | <ul style="list-style-type: none"> <li>• Received feedback from 4 members.</li> <li>• Suggestions included: <ul style="list-style-type: none"> <li>◦ simplifying or clarifying wording,</li> <li>◦ additional questions,</li> <li>◦ answer options.</li> </ul> </li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| 4. | July 2024 | Interview design session      | <ul style="list-style-type: none"> <li>• Support with sharing the live insight survey</li> <li>• Raised suggestions about interview content: <ul style="list-style-type: none"> <li>◦ a split of focus between travel issues and solutions;</li> <li>◦ going into greater depth than survey allows.</li> </ul> </li> <li>• Raised suggestions on interview conduct and accessibility: <ul style="list-style-type: none"> <li>◦ providing example questions in advance;</li> <li>◦ offering different modes e.g. video call/audio/chat;</li> <li>◦ option to add more detail via email after the interview;</li> </ul> </li> </ul>                                                                                                                                                                |



|    |                                                         |                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|----|---------------------------------------------------------|-------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|    |                                                         |                                     | <ul style="list-style-type: none"> <li>o offering an introduction call to discuss accessibility requirements;</li> <li>o helping with using Teams;</li> <li>o allowing carers or supporters to attend;</li> <li>o other support we can offer.</li> <li>• Raised suggestions on who to interview:               <ul style="list-style-type: none"> <li>o majority autistic people with some parents/carers for those who may not be able to take part themselves;</li> <li>o prioritise people who struggled to complete the survey;</li> <li>o ensure diversity including complexity of needs.</li> </ul> </li> </ul>                                                                                                         |
| 5. | July 2024                                               | Focus group design session          | <ul style="list-style-type: none"> <li>• Raised suggestions on focus group topics:               <ul style="list-style-type: none"> <li>o transport professionals' level of autism knowledge;</li> <li>o what they are already doing or planning;</li> <li>o demonstrating impact of travel barriers with real life transport stories;</li> <li>o querying second-best options when the ideal is not possible;</li> <li>o understanding what will achieve their 'buy in' to make changes.</li> </ul> </li> <li>• Raised suggestions of who to invite:               <ul style="list-style-type: none"> <li>o mixed modes and varying seniority;</li> <li>o seek to include autistic staff members too.</li> </ul> </li> </ul> |
| 6. | August 2024                                             | Interview discussion guide review   | <ul style="list-style-type: none"> <li>• Received feedback from 5 members on the discussion guide and participant information sheet.</li> <li>• Suggestions included:               <ul style="list-style-type: none"> <li>o Simplifying wording,</li> <li>o More ideas for conversation prompts,</li> <li>o Topics to expand on.</li> </ul> </li> </ul>                                                                                                                                                                                                                                                                                                                                                                      |
| 7. | August 2024                                             | Focus group discussion guide review | <ul style="list-style-type: none"> <li>• Received feedback from 3 members.</li> <li>• Suggestions included:               <ul style="list-style-type: none"> <li>o Staff ideas on overcoming barriers that autistic people may not think of,</li> <li>o Their views on any flaws in current support offer,</li> <li>o Additional context, clarification and positive assurances,</li> <li>o Understanding of autism and travel barriers,</li> <li>o Clarifying language used.</li> </ul> </li> </ul>                                                                                                                                                                                                                          |
| 8. | August 2024                                             | Travel story writing                | 3 members of the CDG submitted travel stories which were later used in Focus Group discussions.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| 9. | November 2024<br>(following a pause for remaining data) | Early findings discussion           | <ul style="list-style-type: none"> <li>• Verified initial broad findings from the insight survey, particularly around solutions.</li> <li>• Raised suggestions on outputs:               <ul style="list-style-type: none"> <li>o using plain, accessible language and easy-read report version so people can choose their level of detail;</li> <li>o graphics and visuals;</li> </ul> </li> </ul>                                                                                                                                                                                                                                                                                                                           |



|     |                         |                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|-----|-------------------------|------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|     | gathering and analysis) |                                          | <ul style="list-style-type: none"> <li>○ 'real world' stories and solutions;</li> <li>○ capturing examples of good practice.</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| 10. | November 2024           | Solution building session and feedback   | <ul style="list-style-type: none"> <li>• Verified more findings from the insight survey and noted particular strong and weak points of user solution ideas</li> <li>• Received additional feedback from 2 members in feedback time after the session</li> <li>• Raised suggestions about solution building workshops: <ul style="list-style-type: none"> <li>○ Prioritising workshop discussion over a survey format;</li> <li>○ Encourage collaborative discussion and working around any barriers;</li> <li>○ Include context from the data;</li> <li>○ Reach out to additional professionals.</li> </ul> </li> </ul>                                                                                                                                                                                                                                                       |
| 11. | January 2025            | Output planning session                  | <ul style="list-style-type: none"> <li>• Verified findings from the output survey and added to the ideas</li> <li>• Raised suggestions about the outputs: <ul style="list-style-type: none"> <li>○ closed captioning on video/audio content;</li> <li>○ ideas for the report title including using pun phrases such as 'road to', and 'mapping';</li> <li>○ approaching transport professionals for targeted resource ideas;</li> <li>○ autistic-led video diary of travel experiences;</li> <li>○ support for professionals' ride-along experiences with autistic passengers.</li> </ul> </li> <li>• Verified and refined solution ideas from interview data</li> </ul>                                                                                                                                                                                                      |
| 12. | March 2025              | Recommendations and report design review | <ul style="list-style-type: none"> <li>• Received feedback from 2 members on the report covers: <ul style="list-style-type: none"> <li>○ They favoured a lighter colour palette</li> <li>○ The designs were reportedly simple and nice to look at</li> <li>○ They suggested increasing contrast of the text/ decreasing vibrancy of the background for ease of reading</li> </ul> </li> <li>• Received feedback from 3 members on the recommendations: <ul style="list-style-type: none"> <li>○ Tone and language were rated as mostly positive and easy to understand – minor edits were suggested and actioned</li> </ul> </li> </ul> <p>Suggestions and reasoning were thought to be well explained</p> <ul style="list-style-type: none"> <li>○ They felt the data was well reflected</li> </ul> <p>Layout and some sections of explanation edited to improve clarity</p> |
| 13. | (Post-project)          | Evaluation session                       | <p><b>Upcoming</b> - intended outcomes</p> <ul style="list-style-type: none"> <li>• Verify evaluation plan to assess impact of the project and outputs;</li> <li>• Gather member feedback on co-design experience.</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |





## 9.4 Appendix 4: Themes from Interview Analysis

The challenges that autistic people face:

| Basic themes                                                                                                                                                                                                                        | Organising themes         | Global themes                    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------|----------------------------------|
| <ul style="list-style-type: none"> <li>Packed carriages</li> <li>vehicles</li> <li>Lighting, flickering, bright</li> <li>textures</li> <li>Darkness</li> <li>Weather/atmosphere</li> </ul>                                          | environment               | sensory                          |
| <ul style="list-style-type: none"> <li>Noisy people</li> <li>Strong smells</li> <li>Touch, proximity,</li> <li>Germ</li> </ul>                                                                                                      | people                    |                                  |
| <ul style="list-style-type: none"> <li>cancellations and delays</li> <li>stopping mid journey</li> <li>engineering works</li> <li>strike action</li> <li>closures</li> <li>Fear of the unknown happening</li> </ul>                 | unknowns                  | Uncertainty and unpredictability |
| <ul style="list-style-type: none"> <li>every vehicle/carriage is different</li> <li>different routes taken/diversions</li> <li>variability in driver/people/public</li> <li>Other people to queue, where doors open</li> </ul>      | lack of sameness          |                                  |
| <ul style="list-style-type: none"> <li>predicting failure</li> <li>repeated disaster</li> <li>concern about getting on</li> <li>Worry no one there to help</li> <li>Unable to accurately make judgements/estimating time</li> </ul> | catastrophising           |                                  |
| <ul style="list-style-type: none"> <li>overwhelm means avoid</li> <li>travel is tiring so baseline tolerance lower</li> <li>trapped leads to meltdown</li> </ul>                                                                    | overwhelm and fatigue     |                                  |
| <ul style="list-style-type: none"> <li>positioning can't always see facial expressions</li> <li>phone calls</li> <li>need extra processing time due to situational overwhelm</li> </ul>                                             | Barriers to communication | Social communication             |
| <ul style="list-style-type: none"> <li>unclear of social norms</li> <li>confusing social expectations</li> <li>chitchat/small talk</li> <li>social unease</li> <li>pressure to communicate</li> </ul>                               | expectations              |                                  |



|                                                                                                                                                                                                                                                                                                                  |                                        |                                             |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------|---------------------------------------------|
| <ul style="list-style-type: none"> <li>• social rejection</li> <li>• avoiding conflict</li> </ul>                                                                                                                                                                                                                | social fear                            |                                             |
| <ul style="list-style-type: none"> <li>• social shutdown</li> <li>• social discomfort</li> </ul>                                                                                                                                                                                                                 | social response                        |                                             |
| <ul style="list-style-type: none"> <li>• conflicting information</li> <li>• no clear replacement plans and lack of info</li> <li>• lack of clear signposting as stations</li> </ul>                                                                                                                              | misinformation                         | Information accuracy and ability to process |
| <ul style="list-style-type: none"> <li>• format of timetables</li> <li>• making genuine error but couldn't explain events</li> <li>• ticket barriers and what to do is confusing</li> <li>• lack of clarity over approachable/available support staff</li> <li>• auditory processing of announcements</li> </ul> | difficult to process/explain or access |                                             |
| <ul style="list-style-type: none"> <li>• fear of other passengers</li> <li>• fear of theft</li> <li>• one to one in taxi</li> <li>• walking at night/late journeys/delays</li> <li>• fear of hygiene</li> <li>• fear of platform safety</li> </ul>                                                               | fear                                   | safety                                      |
| <ul style="list-style-type: none"> <li>• Hidden disability</li> <li>• Lack of public empathy</li> </ul>                                                                                                                                                                                                          | discrimination                         |                                             |
| <ul style="list-style-type: none"> <li>• Not recognising autism</li> <li>• Autism not understood</li> </ul>                                                                                                                                                                                                      | Public ignorance                       | Lack of public awareness of autism          |
| <ul style="list-style-type: none"> <li>• Masking to avoid being odd</li> <li>• Needs invalidated by others</li> </ul>                                                                                                                                                                                            | Consequences                           |                                             |

### The impact these challenges have on the lives of autistic people:

| Basic themes                                                                                                                 | Organising themes       | Global themes                       |
|------------------------------------------------------------------------------------------------------------------------------|-------------------------|-------------------------------------|
| <ul style="list-style-type: none"> <li>• limits travel</li> <li>• miss out on opportunities</li> <li>• withdrawal</li> </ul> | limited lifestyle       | Loss of confidence and independence |
| <ul style="list-style-type: none"> <li>• loss of confidence</li> <li>• needs not met</li> </ul>                              | disruption to self      |                                     |
| <ul style="list-style-type: none"> <li>• avoid/phobic of public transport</li> <li>• reliant on others</li> </ul>            | prevents travelling     |                                     |
| <ul style="list-style-type: none"> <li>• panic</li> <li>• anticipatory anxiety</li> <li>• increases stress levels</li> </ul> | anxiety and stress      | Mental wellbeing                    |
| <ul style="list-style-type: none"> <li>• overwhelm</li> <li>• meltdown</li> <li>• shutdown</li> </ul>                        | emotional dysregulation |                                     |



|                                                                                                                                        |            |  |
|----------------------------------------------------------------------------------------------------------------------------------------|------------|--|
| <ul style="list-style-type: none"> <li>recovery time</li> <li>anger/frustration</li> </ul>                                             |            |  |
| <ul style="list-style-type: none"> <li>Internalise</li> <li>Self-esteem</li> </ul>                                                     | failure    |  |
| <ul style="list-style-type: none"> <li>reduced energy/burnout</li> <li>recovery time needed</li> <li>fatigue and exhaustion</li> </ul> | exhaustion |  |

### How autistic people try to reduce travel challenges:

| Basic themes                                                                                                                                                                                                                              | Organising themes               | Global themes         |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------|-----------------------|
| <ul style="list-style-type: none"> <li>headphones/noise cancelling items</li> <li>regulatory items, fidget toys, puzzles, food, drink</li> </ul>                                                                                          | Equipment to help focus/protect | Distraction/focus     |
| <ul style="list-style-type: none"> <li>engage in activity to distract</li> </ul>                                                                                                                                                          | Distraction techniques          |                       |
| <ul style="list-style-type: none"> <li>manipulate situations to avoid talking</li> <li>reduce interactions with others by changing behaviour</li> <li>avoiding certain environments or situations</li> <li>communication cards</li> </ul> | Reducing the demands            | Behaviours or actions |
| <ul style="list-style-type: none"> <li>maintain sameness where possible keep to preferred mode, seat or route</li> <li>Choosing mode with most control over</li> </ul>                                                                    | Taking control                  |                       |
| <ul style="list-style-type: none"> <li>Travel with someone</li> <li>Maintain contact with family whilst travelling</li> </ul>                                                                                                             | Family support                  | Support from others   |
| <ul style="list-style-type: none"> <li>Ask for reassurance and use others as support</li> <li>disclose autism</li> </ul>                                                                                                                  | Public support                  |                       |
| <ul style="list-style-type: none"> <li>Checklists and planning resources</li> <li>Live trackers</li> </ul>                                                                                                                                | Resources                       | Planning and prep     |
| <ul style="list-style-type: none"> <li>Emotional prep</li> <li>Preparation, learn routes and times</li> <li>Practise</li> </ul>                                                                                                           | Strategies                      |                       |

### Potential solutions to travel challenges:

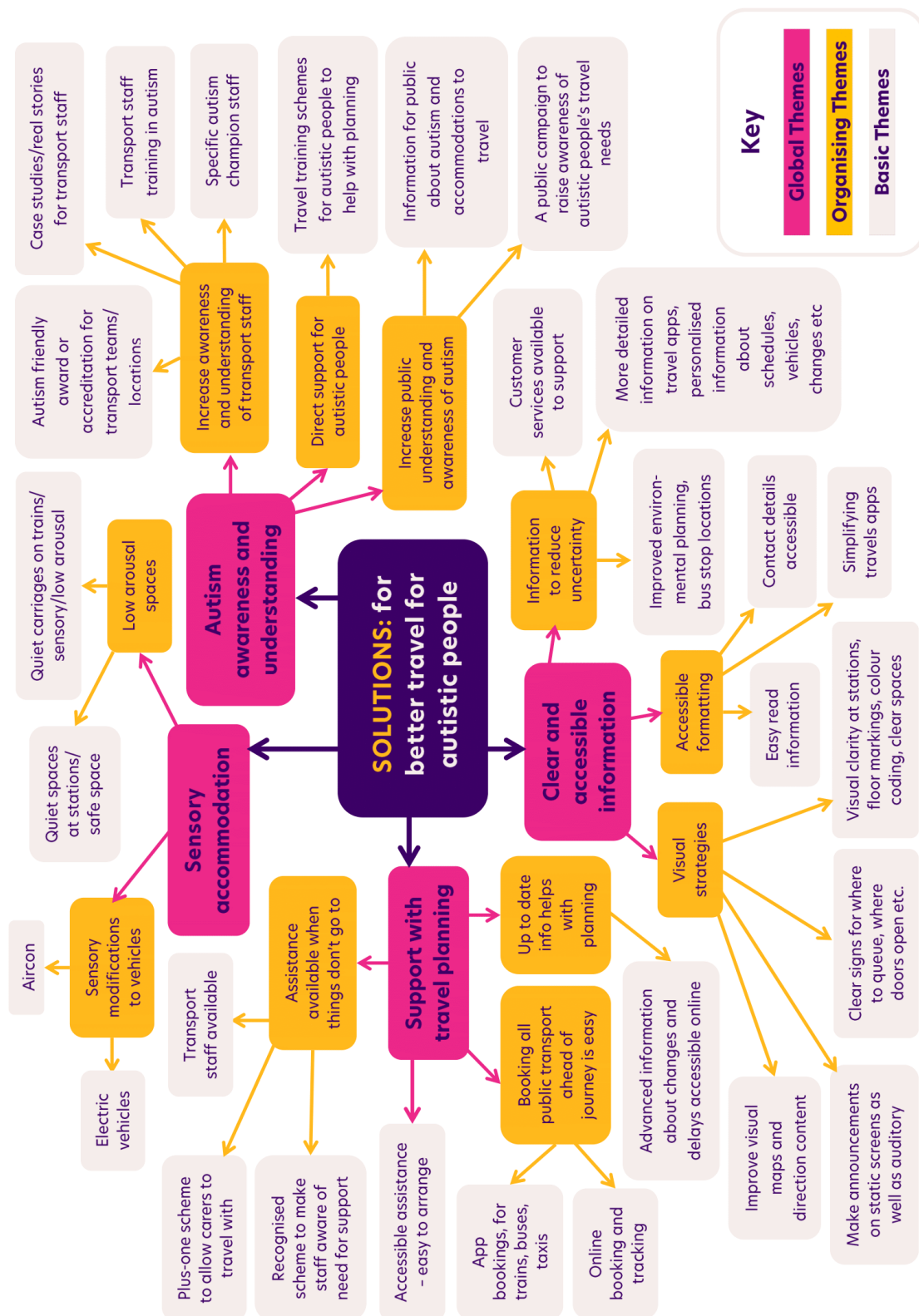
| Basic themes                                                                                                                                 | Organising themes                 | Global themes          |
|----------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------|------------------------|
| <ul style="list-style-type: none"> <li>Quiet spaces at stations/safe space</li> <li>Quiet carriages on trains/sensory/low arousal</li> </ul> | Low arousal spaces                | Sensory accommodations |
| <ul style="list-style-type: none"> <li>aircon</li> <li>electric vehicles for quiet</li> </ul>                                                | Sensory modifications to vehicles |                        |



|                                                                                                                                                                                                                                                                                                                  |                                                         |                                    |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------|------------------------------------|
| <ul style="list-style-type: none"> <li>• more detailed information on travel apps, personalised information about schedules, vehicles, changes etc</li> <li>• customer services available to support</li> <li>• Improved environmental planning (crossings to bus stops are clear at planning stage)</li> </ul>  | information to reduce uncertainty                       | Clear and accessible information   |
| <ul style="list-style-type: none"> <li>• Visual clarity at stations, floor markings, colour coding, clear spaces</li> <li>• Improve visual maps and direction content</li> <li>• Make announcements on static screens as well as auditory</li> <li>• Clear signs for where to queue, where doors open</li> </ul> | Visual strategies                                       |                                    |
| <ul style="list-style-type: none"> <li>• accessible formats</li> <li>• easy read information</li> <li>• contact details accessible</li> <li>• simplifying apps</li> </ul>                                                                                                                                        | Accessible formatting                                   |                                    |
| <ul style="list-style-type: none"> <li>• Advanced information about changes and delays accessible online</li> </ul>                                                                                                                                                                                              | Up to date info helps with planning                     | support with travel planning       |
| <ul style="list-style-type: none"> <li>• App bookings, for trains, buses, taxis</li> <li>• Online booking services</li> </ul>                                                                                                                                                                                    | Booking all public transport ahead of journey is easy   |                                    |
| <ul style="list-style-type: none"> <li>• Accessible assistance – easy to arrange,</li> <li>• recognised scheme to make staff aware of need for support</li> <li>• Plus-one scheme to allow carers to travel with</li> <li>• More staff available to help</li> </ul>                                              | Assistance available when things don't go to plan       |                                    |
| <ul style="list-style-type: none"> <li>• Transport staff training in autism</li> <li>• Specific autism champion staff</li> <li>• Case studies/real stories for transport staff</li> <li>• Autism friendly award or accreditation for transport teams/locations</li> </ul>                                        | Increase awareness and understanding of transport staff | Autism awareness and understanding |
| <ul style="list-style-type: none"> <li>• A public campaign to raise awareness of autistic people's travel needs</li> <li>• Information for public about autism and accommodations to travel</li> </ul>                                                                                                           | Increase public understanding and awareness of autism   |                                    |
| <ul style="list-style-type: none"> <li>• Travel training schemes for autistic people to help with planning</li> </ul>                                                                                                                                                                                            | Direct support for autistic people                      |                                    |



## 9.5 Appendix 5: Example Visual Representation of the Themes



## 10 Further Information

### 10.1 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.



### 10.2 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.



## 10.3 Resources



More Empowering Autistic Travel resources will be added to our website in Spring/Summer 2025

[www.autism.org.uk](http://www.autism.org.uk)



Email address for enquiries:

[research@nas.org.uk](mailto:research@nas.org.uk)