

**People with Non-Visible
Impairments' Attitudes and
Experiences of Transport
Qualitative Research**

**Ipsos MORI report for the Department for
Transport**

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1 Executive Summary

Overview

A 2015 Rapid Evidence Review on disabled people's barriers to transport found that, **although the impact on travel was well understood for people with mobility and sensory impairments, there was a lack of evidence on the impact of non-visible impairments.**

To address this, the Department for Transport (DfT) commissioned this research to interview **20 people with non-visible impairments** about their **attitudes and experiences with transport, and how they thought transport interventions might improve their experiences.** Interviews were conducted across England and included those with the following non-visible impairments: autism spectrum disorder (ASD), learning disabilities, mental health impairments and memory impairments.

Key findings were that **using public transport was important because it provided independence, confidence, a sense of achievement, and freedom** to commute, attend health appointments, lead full social lives, and travel farther afield. However, **many experienced a variety of barriers** when using transport because of the way their impairments manifested. Participants had **difficulties processing and retaining information and communicating with others.** This resulted in **anxiety, stress, and a lack of self-confidence,** especially if travelling alone.

The most issues were reported on bus journeys, despite them offering the most potential benefit because participants can make frequent, local trips. **Many avoided buses and travelled by car instead.**

Key barriers:

- **Communicating with others caused anxiety.** Communicating with others could draw attention to the participant and cause them to feel embarrassed about their communication style or ability. This was a particular concern when booking a taxi, talking to taxi drivers or asking transport staff questions.
- **For buses, it was difficult to plan journeys in advance or find out fare information in advance because of a lack of cohesive information across bus company websites.** Planning journeys in advance was important to reduce both the stress of new environments and the need to communicate with others. Some participants also reported being particularly anxious about not having the correct bus fare if paying by cash.
- **There was a lack of real-time information.** This includes bus waiting times, bus journey length, bus and train onboard communication, and the impact of delays. This is important to participants because they do not want to have to communicate with others. Changes to routes or journey time also triggered stress.
- **Peak-time buses were often overcrowded and involved close proximity with others.** A lack of personal space caused participants to become anxious.
- **Personal safety when using public transport was an issue for those worried about being targeted because of their impairment,** when travelling alone, or when transport was overcrowded.
- **Cost of using public transport was a problem.** Taxis were expensive to use on a regular basis and buses were expensive in some areas. Driving was cheaper or comparable to public transport in some cases.
- **New and busy environments were difficult to manage** because of the need to process new / multiple types of information and the discomfort of proximity to crowds.

Trains presented fewer barriers than buses as interruptions were less likely. Trams were viewed positively as a reliable mode of transport, with no unpredictable changes to routes or timetables. Cars, walking and taxis all provided more flexibility and control over journeys.






Participants coped with the barriers by using interactive maps and journey planning apps. These helped to reduce cognitive processing load when planning journeys, allowed for more informed choices, and reduced feelings of uncertainty and anxiety while travelling as the technology can calculate alternative routes when journeys were delayed or disrupted. Other coping methods included: travelling with someone, travelling at less busy times, using other modes of transport such as cars or taxis, and phoning family members for support whilst en-route.



















Headline themes


Using public transport was important to people with non-visible impairments because it provided them with **independence, confidence, a sense of achievement, and freedom**. Transport users were able to commute, attend health appointments, lead full social lives, and to travel farther afield on holiday. **However, there were barriers towards using transport, and many felt more relaxed when accompanied on journeys.**

Those who were confident with technology used journey planning apps and interactive maps widely as they helped with planning journeys and allowed for more informed decision making whilst travelling.




Current experiences of transport

-  **Participants felt a greater sense of control over route and journey times when either driving/ being driven.** Participants with autism who drove themselves experienced some issues processing information and managing other drivers on the road. Although this was stressful, it was preferable to using public transport, and the journey was felt to be comparable in terms of cost.
-  **Taxis were used by those travelling alone, and by those travelling at night.** They provided more flexibility and control over journey length, less exposure to busy or noisy environments, information about waiting times, and potentially less need for interactions with others. However, **affordability, and access to taxis in rural areas were two key issues**. In addition, booking taxis by phone was a barrier for participants who lacked verbal fluency.
-  **Buses offered access to many local places and were used for short, frequent journeys.** However, **participants reported more issues about buses than other transport modes**. Navigating online timetables was difficult. Fares in some areas varied by the time of day or day of the week making spontaneous journeys difficult if paying by cash. Many expressed concerns about the lack of real-time information when considering whether to wait for a bus. Bus drivers were often perceived to be impatient and potentially inconsiderate when communicating with passengers with non-visible disabilities. Walking was more common in peak hours when buses were crowded as participants worried about personal safety, comfort, and proximity to others.
-  **Train journeys were relatively straightforward to plan and were used more widely for short or direct routes. Booking websites were useful and offered comprehensive visual information about routes, journey times and fares.** However, the noise and 'busyness' of large stations was overwhelming and was a barrier for some. Low visibility of staff on train platforms contributed to anxiety about getting on the right train. Participants wanted access to more visual information on trains to confirm route and journey time. Lack of accessibility at stations affected those with mobility issues.
-  **Experiences of using trams in Manchester were generally positive** as they were spacious and more comfortable than buses/trains, and audio-visual information was provided on board. Users felt informed and relaxed by the fixed routes used and reported there were few delays or disruptions.

Barriers to using public transport and how these are managed	
The mode of transport these apply to are shown by icons in the box	
<p>Information needed to plan journeys</p> 	<ul style="list-style-type: none"> It was difficult to plan bus journeys using bus company websites, or find out bus fare information in advance. Bus fares varied across weekday / weekend in some areas preventing some from using the bus. Journey apps and interactive maps helped to plan routes but did not overcome lack of advance knowledge about bus fares
<p>Lack of real-time information</p>  	<ul style="list-style-type: none"> Many were unable to determine waiting times (e.g. at bus stops), journey lengths, and the impact of delays (e.g. on buses with limited on-board information or last-minute changes to train times or train platforms) To overcome anxiety/ lack of confidence to ask questions, participants used interactive maps or train apps whenever possible. Some walked short journeys instead of taking a bus, drove themselves or asked to be driven
<p>Lack of personal space / comfort</p>  	<ul style="list-style-type: none"> A common barrier exacerbating anxiety involved peak-time buses which were overcrowded and involved close proximity to others. Many avoided these buses and walked for part / all of journey. Some preferred to drive or asked others to drive them.
<p>Communicating with others</p>   	<ul style="list-style-type: none"> Those with impaired communication skills did not want to talk to others due to embarrassment and anxiety about their communication style or ability. To overcome this, some used journey apps, interactive maps and/or phoned family members for support whilst using public transport rather than approaching staff
<p>Personal safety</p>   	<ul style="list-style-type: none"> Some feared being targeted because of their impairment (especially lone males at night) and some females were concerned about using taxis with male drivers To overcome anxiety some preferred taxis, drove themselves or asked others, or did not travel alone
<p>Access to transport</p>  	<ul style="list-style-type: none"> It was more difficult to make spontaneous journeys in rural locations where buses or taxi services were less available / reliable, and more walking was required to access transport Some drove or asked others to drive them, or took taxis when not able to make spontaneous journeys
<p>Cost</p>  	<ul style="list-style-type: none"> Taxis were unaffordable on a regular basis and buses were expensive in some locations. Driving was cheaper or comparable to public transport for some journeys
<p>New environments</p>   	<ul style="list-style-type: none"> It was difficult to process and remember multiple types of information in new environments or when taking a journey for the first time especially if travelling alone Participants were likely to travel with a carer / family member until they were more confident. Some preferred to drive or take a taxi to avoid others and be more confident about journey length / arrival time

<p>Busy environments</p> 	<ul style="list-style-type: none"> • Proximity to crowds and noise, together with the need to process and remember multiple types of information was more difficult in busy or noisy environments such as bus/ rail stations / train platforms. Participants were likely to avoid busy environments especially if unaware of quiet spaces • Ways of coping including driving, taking a taxi, or travelling with someone else
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Public transport could better meet needs by offering interventions to reduce cognitive processing, improve retention of information and make participants feel more informed whilst planning and en-route.

Potential interventions suggested by participants split by journey stage	
	<p>Planning journeys</p> <ul style="list-style-type: none"> • offering journey apps and local bus company apps tailored to user needs • wider use of online booking for taxis, to enable transport users to be more independent when planning journeys and overcome limitations with communication skills • simplifying bus timetabling information on bus company websites
	<p>Using technology when travelling</p> <p>Provide more:</p> <ul style="list-style-type: none"> • real time information, for example dot matrix boards at bus stops; • visual information, for example route maps on buses, and / or visual information about stops en-route • journey apps tailored to user needs, for example, suggesting less busy routes • wider use of non-cash payment systems (such as the Oyster system used in London) to allow transport users to make more spontaneous and frequent journeys, especially by bus
	<p>Helping those less confident with technology</p> <ul style="list-style-type: none"> • communicate widely that staff are trained to help people with non-visible impairments • offer free assistance cards to help transport users overcome any anxieties about communicating with transport staff, and to inform staff of individual needs • widen the availability of the Companion Bus Pass and publicise its benefits, to allow transport users to travel more with others and to feel more relaxed whilst travelling

2 Introduction

Background and research aims

Last year a fifth of the UK population reported having a disability¹, and because of this, experienced difficulties accessing and using transport. In many cases these challenges can prevent disabled people from travelling which can lead to social isolation and limited access to vital services. Consequently, the government has set out a vision in its Inclusive Transport Strategy (ITS) to ensure disabled people have equal access to transport as everyone else by 2030, with assistance where physical infrastructure remains a barrier.

A literature review commissioned by the DfT in 2015 identified a lack of understanding of non-visible disabilities and there remains a large evidence gap concerning interventions needed to improve accessibility among people with cognitive, learning, behavioural and mental health impairments. Without this knowledge there is a risk that policy decision-making will be misinformed.

This qualitative research study aims to address this evidence gap and develop DfT's understanding of how different impairments impact transport and what impact different policies might have on people with 'non-visible' disabilities.

This research is exploratory to provide further insight ahead of the first stage of the ITS evaluation in December 2020. The evaluation itself would likely involve more detailed research on particular interventions. This research, therefore, is preliminary, to inform any further work produced prior to the results of the ITS evaluation being available.

Research objectives

The research consisted of three questions:

- How do disabled people with cognitive, learning, behavioural and mental health impairments experience travel in their day to day lives?
- What are the barriers to those with such impairments accessing transport?
- What interventions could help to improve their journeys?

Methodology and Sample

The research consisted of **20 x 1.5 hour face to face depth interviews** with interviews split equally across participants with the following types of impairment:

- Autism or Asperger's Syndrome

¹ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/791271/family-resources-survey-2017-18.pdf

- Learning disability (Down's syndrome / those with IQ under 70)
- Mental health impairments (anxiety or depression)
- Dementia, or memory loss through brain injury

A qualitative approach was taken as it allows for the exploration of the breadth and depth of people's experiences. It therefore only reflects the experiences of people recruited for this research and is not statistically representative. Individual interviews were considered the most suitable method for this study as interviewing participants one to one enabled the research to be participant-led, so that the most pertinent issues for participants were explored, rather than those identified on the discussion guide. A ninety-minute interview allowed for exploration of individual's day to day life, their experiences using transport and ideas for interventions. The discussion guide is included in the Appendix of the report.

Face to face interviews were considered more appropriate than a telephone interview, focus group or other qualitative methods. Interviewing participants in their home provides a relaxed environment, where it is easy to take breaks if required, and which is important when discussing sensitive topics. A face to face method also allowed researchers to establish and maintain rapport with participants which is harder to achieve over the phone or online.

Ten interviews involved carers. These carers were family members and were included so they could offer support to participants with more severe conditions. Where required, carers gave insights about the participant's day to day life and experiences of using transport on behalf of the participant, especially if the participant experienced problems communicating.

Interviews were conducted across different types of locations including a market town, a commuter town, a larger city and a rural location. Locations included: Yate (near Bristol), Reading, Watford, St. Albans, Sutton Coldfield, Manchester, Diss, Brandon and Weeting (Norfolk). By covering a range of locations, we were able to explore differences in transport accessibility and availability.

Other key sampling criteria included:

- A spread of ages (18+) - to explore how age may impact on motivations and barriers and accessibility issues
- A spread of males and females - to explore if there are any issues related to gender
- A spread of socio-economic groups - to explore issues such as affordability of travel
- The majority of participants were using at least one of the following transport modes: bus, train, tram, car, taxi, a transport service provided by local council. This allowed us to explore motivations to use different types of transport.
- Ability to use transport modes were spread across the following and allowed us to explore motivations in detail:
 - Able to use range of modes with limited or no difficulty
 - Able to use range of modes with some difficulty
 - Cannot use any form of transport
- The sample also aimed to include a spread of barriers including proximity to transport mode, cost, physical barriers, and emotional barriers such as motivation and confidence

Please note that throughout the report evidence is provided through participant verbatim comments. Verbatims have been attributed by providing information on type of impairment. Location is also attributed, except where this would compromise individual anonymity.

Strengths and limitations of the research

When considering these findings, it is important to bear in mind that a qualitative approach provides insights on a range of attitudes and opinions of participants in detail. Although a discussion guide was used to make sure that the main topics were addressed, interviews are participant-led and are not designed to provide a systematic exploration of every question or topic included on the discussion guide. Qualitative research provides an insight into the key reasons underlying participants' views and findings are descriptive and illustrative, not statistically representative. In other words, these findings give a good indication of the breadth of issues and views held by those with non-visible disabilities. It is reflective but not quantifiable and so can say nothing about the prevalence of an idea, for instance, nor can they be extrapolated to the whole population. Furthermore, this research consisted of a relatively small sample; a more extensive piece of qualitative research could provide additional depth and nuance.

Social research is subject to potential biases as participants agree to take part in the research, introducing the potential for a self-selection bias. In this study, participants may have become more committed to the study as they were screened to confirm their consent to participate twice - at recruitment stage, and at the beginning of the interview. Another risk associated with self-selection is that participants may have made their decision to participate to highlight a particularly negative experience, leading to over-consideration of a specific issue.

An additional bias of qualitative research is the researcher effect, where the researcher may unintentionally influence a participant's responses through non-verbal communication or identifying their own feelings about a topic.

A quantitative study among this type of audience would have allowed for a higher number of participants to be sampled across a greater number of locations, providing stronger evidence on the variables explored and allowing for comparisons across variables, such as impairments, transport modes, and locations. However, a quantitative methodology introduces its own limitations, for example, quantitative research allows comparisons across variables to be made. However, it is hard to gain richness in terms of depth of feelings and emotions.

3 Living with impairments

General impact of impairments

This section of the report describes how participants live with and manage their impairments on a day to day basis. How the impairments affect motivations to travel are covered in the next chapter of the report.

Autism

Participants with autism/Asperger's in our sample had all been diagnosed as adults. One participant was diagnosed with ADHD as a teenager and after several years was given the diagnosis of autism. People in this category have social difficulties that may require support as they can find it difficult to initiate conversations with others, may show inflexible behaviours, may find it difficult to cope with new environments, and may need help with organisation and planning.

Other participants described living without a diagnosis until in their 40s and were also experiencing episodes of poor mental health involving periods of anxiety and depression. One participant had experienced a breakdown involving periods of interaction with NHS mental health services before their autism diagnosis. Since diagnosis, a small number had received or were still receiving counselling. One participant had been recently diagnosed with dyspraxia and was also prone to anxiety and depression. One person had been assigned an 'emotional support' dog which helped to alleviate her anxiety and she aimed to travel with the dog as much as possible.

Levels of self-confidence among participants varied. Routine behaviours, structure, repetition, and checking all helped to minimise feelings of uncertainty and helped participants to cope with change and to manage day to day life, especially when not at home. Impairments fluctuated in severity with the possibility of having panic attacks or 'burnout' on some days if they attempted to do too much. Others described becoming overwhelmed and emotional. One person was using a mindfulness app to help with their anxiety which they found useful.

"I cry an awful lot more than my 6-year-old son because I can't cope with situations"

"I'm very good with what I know but if things change I'm not OK"

These participants described themselves as visual learners who struggled to understand verbal instructions. Speaking on the phone was avoided by some, and when communicating with others, many found it difficult to engage or ask questions of others or express themselves clearly and coherently, especially in busy and noisy environments or when feeling nervous in a new situation. Understanding of jargon or terminology was problematic. Communication difficulties made participants feel embarrassed because of the attention they were drawing to themselves, further compounding their anxiety.

However, many were working, either on a part or full-time basis, and some had families, so their responsibilities meant they needed to travel on a regular basis.

Mental health impairments

Participants in our sample experienced anxiety and depression, with some also experiencing either claustrophobia or agoraphobia. Participants reported spending as much time at home as possible being supported by friends and family.

² <https://www.medicalnewstoday.com/articles/325106.php>

They also discussed how their impairment affected their self-confidence and some had received therapy or attended support groups which they felt had helped them manage their impairment. Some also experienced other health issues and / or physical impairments.

“My kids ... and my friends know nothing about what I'm really like. I avoid situations or just do what I feel comfortable with. I'd love to go to Bristol with them, but I can't do it, I overthink things so need to distract myself. Only my husband and one friend truly know. My husband is my walking stick in a way. It's been a problem most if not all my life. I can feel overwhelmed. I hate going to the hairdressers - you're sat there for 2 1/2 hours. I didn't like feeling that I can't get away. It's a nightmare”

Some were either currently on medication or had spent periods of taking medication over the years. Some experienced panic attacks or other physical symptoms such as heart palpitations or sweating when anxious, particularly when in busy or noisy places. These participants, like those with autism/ Asperger's worried about what others thought of them and felt others were judging and criticising them.

The severity of a participant's impairment may influence their motivation to leave home on any given day, and travel may be restricted to days when they felt well. Some participants indicated that they felt more comfortable travelling with friends or family. In addition, responsibilities outside the home requiring the use of public transport, such as taking children to school or shopping, were shared with family members when available. One participant worked from home on a part-time basis, but at times needed to travel to meetings at different locations in the UK.

Learning disability

Participants in our sample experienced issues with remembering information and family members provided valuable emotional and practical support with planning and completing paperwork. In terms of communication, carers felt participants' reading ability was better developed than writing, and slower speech processing resulted in a reluctance to use phones to communicate with others unless it was family. Some were happy to text on a phone but did not want to use apps.

Participants expressed a low tolerance for and low self-confidence when in busy and noisy places and demonstrated a general reluctance to ask for help. In terms of being out of home, some participants described being driven to colleges or day centres by their family members or community transport. People with a learning disability were less motivated to travel alone or were not considered sufficiently skilled to do so by their family because of a poor sense of direction. It was easy for them to become lost and walking long distances was difficult.

Dementia

Participants in our sample with dementia had generally experienced a gradual decline in their health. A small number of participants had mobility issues requiring them to use a Zimmer frame or wheelchair. One participant had a dementia-related sight condition affecting her ability to interpret visual information such as signs, symbols and colours, and an inability to read scrolling information. A small number of participants had also recently lost their partners which carers felt had contributed to their general decline.

Their general motivation to leave their home had decreased, with some carers saying their parent/ partner slept a lot during the day. One person who lived in a rural location was visited at home on a regular basis by some health professionals, friends and family, and others such as her local vicar. This participant had always travelled with her partner

and had not used public transport for many years. When she left home, it was usually when driven by a family member to hospital appointments.

Another participant with dementia used to use the bus and wished to continue doing this. But her daughter considered it was no longer safe for her mother to travel by herself because she could no longer communicate coherently or make effective decisions. Therefore, the daughter now either drove her mother to visit family members or to go shopping, or used taxis to take her to hospital appointments.

“[My mother] once got her next-door neighbour to take her in his car to visit her sister. I had no idea she had gone there until I got a phone call from my Aunt asking me to pick her up”

4 Attitudes towards using transport

4 Attitudes towards using transport

General motivations and barriers to travel

Participants and/ or carers often had mixed feelings towards travel.

Being able to travel allowed participants to access important places such as hospitals, work, college, friends and to enjoy social trips and holidays. Anyone who was able to travel by themselves experienced a feeling of independence and self-confidence and a feeling of achievement in terms of managing their impairment. This was an important component for younger participants who had just started work or were attending college. Dementia carers wanted to maintain as normal a life as possible for their loved one for as long as possible.

However, participants also talked about issues related to their impairments which were more difficult to manage when travelling, such as communicating with others and processing information. Many preferred to travel with someone else as they felt more relaxed, and safer than when travelling alone. One participant travelled with an emotional support dog who helped to alleviate her anxiety. This was generally successful, although the participant felt excluded from using taxis because of her dog. Carers of participants with learning disabilities reported that they or a related professional often accompanied their family member on journeys because of their impairments.

“We tried travel training, it was to try and get her used to the bus route, but she found it a bit scary, especially when the bus didn’t turn up”

Learning disability, Carer, Yate

“I can’t always get out what I want to say especially when it’s noisy or I have to rush it and I struggle sometimes to know what to do because I can’t work it all out”

Autism, Manchester

Many reported feeling anxious when making journeys involving new routes or using multiple modes of transport. The amount of cognitive processing and decision making involved increased their overall sense of anxiety and ability to manage their impairment.

“It’s better when I’m not alone because I can concentrate on the kids and not worry about what people think of me. I always feel people are staring at me even though they’re probably not. It’s not just on the buses, it’s any confined area”

Mental health impairment, Manchester

Lack of choice or availability of transport in their local area may add to participants’ anxiety because journeys required more planning. Whilst visual aids and navigation tools such as Google maps and / or satnav seemed to provide some respite from the effects of cognitive processing and decision making, other aspects of travel outside their control, such as deviations and disruptions to journeys and the need to interact with others such as staff and passengers, added to anxiety.

Impact of impairments when considering travel

The following table summarises the types of issues participants experienced when travelling as a result of their impairments. More detail on each of the issues is given in the paragraphs following:

Processing information	<ul style="list-style-type: none"> Assessing and combining multiple types of information simultaneously may make decision making whilst travelling more difficult, for example when learning new routes, adapting routes because of delays and disruptions, or interpreting new environments More likely to affect anyone travelling alone
Retaining information	<ul style="list-style-type: none"> Remembering information may be more difficult especially if using a new route or travelling infrequently More likely to affect those with learning disabilities and autism
Communicating with others	<ul style="list-style-type: none"> Many felt anxious about communicating with staff and passengers because they worried they would not be understood, and often avoided interacting with others while travelling
Mobility	<ul style="list-style-type: none"> Some participants also experienced mobility issues; those using mobility aids, and some mothers travelling with children in buggies/prams, experienced some accessibility issues or concerns about their personal safety

Processing information

Those with autism, mental health impairments and learning disabilities experienced similar issues when processing information. These participants (or their carers) described difficulties when assessing and combining multiple types of information at the same time, such as when travelling in new environments, learning new routes or having to react to disruptions to their journeys. These participants found it difficult to focus on verbal instructions in particular and preferred to take in information visually where possible, such as when using Google maps. Those who were not confident using technology would print out maps at home or write things down.

Retaining information

Retaining information was an issue for those with dementia or short-term memory issues, and those with learning disabilities. Carers of participants with learning disabilities described how family members had received travel training to help them develop strategies for retaining information. Others wrote down information if not confident using technology or used Google maps or other apps such as trainline.com

“He’s unable to do it himself so his sister looks on the computer for which buses to catch, where to get on and off and how much they cost if it’s peak time and then writes it all down for him to take with him. He will ask the bus driver where to get off but sometimes gets a funny look. None of the local buses tell you what stops are, like the trains do”

Learning disability, IQ under 70, carer, Manchester

Communicating with others

Many participants preferred not to speak on their phone when travelling, using it to search information, as a navigational aid (via Google maps) or text. Participants with autism and learning disabilities felt they could not always express themselves clearly or coherently when asked to speak to someone on the phone and felt more anxious when in new

situations or in busy or noisy environments such as rail stations. Many wanted to avoid embarrassing themselves if they could not communicate clearly and therefore avoided interacting with others where possible.

"I feel uncomfortable around other people. I can't always read their body language or know if they're a danger. You don't know what they're like or what they're going to say to me or what might happen. [if I have to speak to staff] I try to put a confident face on and not rush what I need to say. Once I've got their attention I feel like I'm on a stage and I've got to say my bit now, so I get butterflies and stutter."

Autism, Manchester

"I just don't like being around strangers. I have a fear of having a panic attack and showing myself up."

Mental health impairment, Yate

Mobility issues

Mobility issues mainly affected participants with dementia who were using mobility aids such as Zimmer frames or wheelchairs. Where journeys required the use of bus or rail stations participants sometimes became anxious about their safety when using lifts or escalators. Personal safety was also a concern for a wheelchair user travelling by bus who felt that she might be at risk of falling out of her wheelchair on the bus if it was travelling fast. Some participants travelling with young children and using buggies or prams also felt concerned about safety when getting on and off trains. These issues impacted motivation to use transport, for example in busy or peak hours when overcrowding added to safety concerns. These issues are explored more fully in section 5 of the report.

The need for planning

Planning a journey was impacted by a range of factors. Planning frequent journeys was easier as participants usually used the same transport mode and were able to learn the different information processing and decision making required. However, where disruptions or delays occurred, or issues that participants were not aware of, these could cause anxiety unless participants were able to access information to help them understand their options. This was usually performed via Google maps, phoning a family member, and in some cases speaking to transport staff. Google maps was preferred by many as it offered information about a complete journey and included visual aids such as maps and Street View.

"I would like to be able to access more information/ warnings when booking travel about large events like a big football match or concerts so such busy times can be avoided"

Autism, Manchester

Journeys to new destinations required much more planning which potentially involved accessing new information and using new sources, all of which increased the mental effort involved. Participants often looked online for information as this removed the need to phone or speak to someone. Google maps was often used by those confident with technology as this could provide information about a journey from start to finish.

“I don’t use anything other than Google maps. It’s great because it will tell you the bus journey, the train, the taxi, it gives you the time, it tells you where the buses are. I rely on that a lot and you just type in your destination and it’s all there, and it’s simple to use and understand and if you miss your bus all I do is just restart my journey and it will tell me when the next bus is. It is my go-to, I wouldn’t use anything else because that would just confuse me. I don’t plan anything because I would just worry about it and then probably not go.”

Mental health and physical impairments, Reading

Carers of those with learning disabilities often planned journeys on behalf of participants, writing down the key information so it was not forgotten. On some occasions they, or a related professional, also performed a ‘dry-run’ journey so the participant could learn the route and processing and decision making required.

“It might help if the timetables were easier to understand and the numbers of the buses and their route clearer. They’re really hard to fathom out. Maybe they could do a special timetable for people with special needs”

Learning disability, carer, Manchester

Planning when using different transport modes

Planning car journeys

Planning car journeys was relatively straightforward for drivers as participants regularly used navigation aids which advised them of journey time and route. Those who were not confident using technology printed out written instructions.

Planning taxi journeys

Most participants phoned a taxi company to book a journey. This was easier for those who did not experience difficulties with expressing themselves verbally. Where this was more difficult, participants asked family members to book taxis or used an alternative mode if this was not possible. Some booked the same taxi companies on a regular basis and had developed trusted relationships with suppliers as a result. For example, one carer of a participant with dementia was happy for her mother to be taken by a taxi to hospital appointments as the same taxi driver was used for each journey.

Planning bus journeys

When planning journeys by bus, many found that navigating bus company timetables online was difficult and there was a lack of coordination across bus companies. This was more relevant if a participant needed to use more than one bus for a journey. Some with cognitive impairments found the level of detail of timetabling information difficult to manage. Participants with learning disabilities usually relied on carers and family members to plan their journeys for them with bus times and bus numbers written down for them so that journey details were not forgotten and could be referred to later. Some participants had discovered local bus apps which they used and found useful, but these were not mentioned by many participants.

Participants talked about bus fares often varying according to the day of the week or time of day and some were particularly anxious about not having the correct fare to use a bus if paying by cash. Asking the bus driver for additional travel information such as checking they were on the right route or which stop they needed to get off at also caused anxiety as communicating with another person could draw attention to the participant and cause them to feel

embarrassed about their communication style or ability. Bus drivers were often perceived to be impatient and potentially inconsiderate when communicating with passengers with non-visible disabilities.

Planning train journeys

Many participants found planning train journeys to be relatively straightforward using online sites such as thetrainline.com. This website provided comprehensive information including the platform the train would depart from, the number and name of stations visited on the journey, whether the route was direct or required changes, identifying the fare and booking the ticket online. This allowed participants to calculate the cost-effectiveness of train travel vs other modes and allowed the individual to decide if they felt confident managing the journey. Some participants would only travel by train if the route was direct, as changing trains may require more cognitive processing and potential for interactions with others.

A small number of participants were less confident using technology and did not feel confident about buying their tickets online. They had been told by friends that they would pay more as a result of buying at the station but preferred the idea of holding a physical ticket in their hand.

5 Experiences of using transport

5 Experiences of using transport

This section builds on the previous chapter as it explores participants' experiences when travelling via different transport modes. Participants were asked to provide views of their travel experiences across different stages of a journey, from start to destination and this allowed identification of which stage of a journey was most or least problematic.

Walking

Participants mainly described walking in relation to accessing bus stops near their home or destination. A couple of participants living in a rural location both of whom experienced mobility issues sometimes walked to a bus stop if aided by a carer and if they felt well enough. Another participant with a mental health impairment described basing her decision to walk to a bus stop on the length of time she would have to wait for a bus and the weather on the day. For these participants, alternatives to walking would involve asking a family member to drive them either to the bus stop or their destination. If available some participants drove to their destination or took a taxi as an alternative to walking. This was considered easier to manage especially if their journey was dependent on reaching their destination at a specific time.

The carer of a participant with a learning disability also reported that his son often walked to/ from his day centre. Although his intention was just to walk to the local bus stop, buses during peak hours were considered too crowded, and he therefore walked all the way to his destination instead.

Travelling by car

In summary, motivations and barriers for using cars are shown:

Motivations	Potential barriers
<ul style="list-style-type: none"> Control over journey departure time and route Travelling with trusted individuals who understand their impairment No communication issues Sense of empowerment and/or independence 	<ul style="list-style-type: none"> For drivers - potential to get lost when taking new routes / diversions For drivers - issues processing information from signs, navigation aids, and other drivers on the road Difficulty finding parking at destination

Drivers tended to be participants with mental health impairments, autism / Asperger's, or carers of those with dementia or learning disabilities. Although driving could be a stressful experience for participants with impairments, overall, it instilled a sense of independence, autonomy and confidence. Many travelled locally with journeys often limited to a five-mile radius and to places they knew well e.g. to work or for social activities. If parking was a problem, public transport was considered as an alternative.

The key issue for drivers with autism/ Asperger's was the ability to manage the way they processed information while driving, to avoid becoming overwhelmed. Driving meant being able to stop en-route if required and this was a necessity for drivers with autism / Asperger's who experienced anxiety triggers when taking new routes, travelling on the motorway or on busy roads. Overall, their impairments did not stop them from driving as the benefits of this mode of transport outweighed the disadvantages.

“The act of driving is OK but sometimes I feel very overwhelmed and have a bit of a breakdown.”

Autism, Norfolk

“I can drive 4 times round a roundabout without knowing where to make the right turning”

Asperger's, Watford

In the rural location, participants and carers discussed the prevalence of diversions/ roadworks in their area which extended the length of their journey, but overall, these were managed well.

Carers who drove family members felt this reduced or removed the stress and anxiety participants experienced with information processing when taking public transport. In addition, participants as passengers felt more relaxed and in control as they were with trusted individuals who understood their impairments, unlike staff or passengers on public transport.

Carers of older participants, notably those with dementia, preferred to drive as this offered more flexibility especially where their family member experienced mobility issues and required wheelchairs or Zimmer frames and potentially luggage, depending on the journey type.

Getting lost was a potential stressor for some when driving so navigational apps and devices (e.g. satnavs) were used by those with smartphones as they reduced the cognitive load and decision making about the route being taken. Those without a smartphone printed out route instructions or wrote them by hand and learned them as much as possible. One participant with autism noted they had had an accident when using the motorway and drove less now, as a result.

Participants liked that navigational aids clearly signposted diversion routes and alerted them to delays in advance. They could also alleviate stress when arriving at a new destination as they helped to find the nearest car park.

Parking was a potential barrier to driving for some, especially in town centres or when wanting to park at train stations. An inability to park, especially for passengers with mobility issues, was raised as a major concern, as well as not knowing the cost of parking. Some participants were currently, or had been, Blue Badge holders and reported that having a Blue Badge does make things easier but still experienced problems finding disabled parking spaces, especially in stations.

[when being driven by her husband] “I feel more in control in the car and have the option to turn back easily anytime if I don’t feel up to it. I have a small radius for local familiar routes...a safe radius from home is up to 4 miles. I’ll drive myself for this, otherwise I’ll use public transport”

Mental health impairment, Yate

“When going to the station I’m more likely to get the bus because parking for the whole day is quite expensive but if I’m not confident that I can get there without panicking, I’ll take the car”

Mental health impairment, Watford

Travelling by taxi

In summary, motivations and barriers for using taxis are shown:

Motivations	Potential barriers
<ul style="list-style-type: none"> Control over journey departure and return times Travelling with trusted suppliers Journey tracking while waiting for taxi to arrive Ability for drivers to help passengers with mobility issues 	<ul style="list-style-type: none"> Limited availability at certain times of the day in rural location Anxiety for participants with autism / Asperger’s when booking over the phone Some concerns over personal safety / comfort Ability to afford frequent journeys Feeling excluded if travelling with an animal

Many of the main motivations for travelling by car apply equally to taxis, in terms of ease of travel experience and fewer interactions with strangers. Similarly to cars, taxis provide direct transport from A to B, without the need to worry about parking, and can be used more easily than public transport by those with mobility issues who find it difficult to access stations using lifts or escalators. However, in some instances, taxis had turned up without the facilities to accept wheelchairs.

Participants and carers tended to favour local taxi firms who they felt they could trust to be sensitive towards their/ the participants’ needs and who were willing to provide help, for example, assisting an older participant with dementia and/ or mobility issues in and out of the taxi. These taxi companies could be trusted to take participants to hospital appointments or pick them up. Taxi firms which offered the ability to send a text message to confirm they were on their way or the potential for tracking the taxi en-route also appealed to carers as this provided additional reassurance about participants travelling alone.

“I will take Mum out in the car but when I’m not around we use taxis. I know the drivers, they help Mum into and out of the taxi, and I phone them up to make sure she got there OK. She needs to be taken door to door”
Carer for mother with dementia, Watford

Participants with autism or learning difficulties disliked having to phone a taxi firm to make a booking because they experienced communication difficulties, especially when stressed or when speaking to strangers. For some, this could act as a barrier to using a taxi if travelling alone. Others would phone family members to make the booking on their behalf who would explain their situation to the taxi company on behalf of the participant.

“Ordering a taxi is my main problem as I find it very stressful and I don’t understand what the person on the phone is saying or asking me. I don’t know what to say when they ask where I want picking up. I think they think I’m drunk. They’ve put the phone down on me...it’s a bit easier in person. I’m fine when I’m on my way.”

Autism, Manchester

Communicating with others on the journey was also an issue for some. Whilst a taxi could involve a conversation with a taxi driver which might cause anxiety, it was preferable to the potential anxiety when travelling on other transport modes and offered the participant more control over their journey en-route.

“Anxiety is exhausting so I might get a taxi back home [from a shopping trip] and that’s easier for me than the bus as I can get them to stop any time I want. I’m more in control and my anxiety is too”

Mental health impairment, Yate

For a rural participant, taxis were a necessary regular transport mode due to a reduction in local bus services, and/ or irregular bus timetabling across available bus services. A small number of participants with mobility issues used taxis regularly to access medical appointments at their GP or local hospital. If it was not possible to obtain a medical appointment to coincide with available bus times, participants used taxis to avoid lengthy waits at bus stops. Another participant in a commuter town also used taxis to her local rail station as she felt anxious waiting at bus stops, especially where there was no live information about waiting times.

A barrier to travel for the rural participant involved the need to pre-book taxis to be confident of securing a taxi when needed. Although there were several local suppliers in the area they tended to favour regular ‘school run’ bookings and often stopped offering their services after 5pm, making spontaneous evening journeys much more unlikely.

Some concerns were raised around perceived personal safety when travelling by taxi. Females felt less comfortable travelling in a taxi alone with a male driver, especially if at night, and others commented on not feeling comfortable if drivers adopted an aggressive or fast driving style. In addition, one male participant felt that his personal safety might be compromised in a taxi if he found it difficult to converse with the driver because of his anxiety.

“I rarely order a cab as I get anxious about the cost. I’ll only get one if I’m sharing with others, as it keeps the price down.”

Mental health impairment and dyspraxia

One participant with Asperger’s preferred to travel with her emotional support dog but felt that she was excluded from taking taxis because they would not accept her animal.

Cost was an issue when deciding whether to take a taxi, especially if the participant did not work and relied on benefits. However, cost was weighed against the relative benefits of taking a taxi and in some cases, a taxi was cheaper than taking multiple buses or when factoring in the cost of parking.

Travelling by bus

In summary, motivations and barriers for using buses are as follows:

Motivations	Potential barriers
<ul style="list-style-type: none"> • Affordability, especially for those who do not have to pay or have a Companion Bus Pass • Relatively short and direct journeys which can save on walking time • No parking issues 	<ul style="list-style-type: none"> • Difficulty navigating timetables and fare prices online • No real-time information at bus stop (except for Reading) • Bus station environment is noisy / busy and low visibility of staff • Bus driver may be unaware of/ inconsiderate towards communication issues • No route information provided on-board • Overcrowding causes anxiety - potential for comments / interactions with other passengers • Speed / stability of bus may cause anxiety about safety concerns • Diversion to routes requires additional information processing/ potential need to interact with driver • Identifying correct destination / bus stop more difficult without on-board route information

Buses were used by people with mental health impairments, cognitive impairments and learning disabilities who usually travelled independently. These participants tended to be frequent bus users using buses for relatively short journeys to reach work or college, and to connect with trains to work/ college/ business or leisure. Buses tended not to be used by those with dementia even if travelling with carers, especially where the participant experienced mobility issues. The amount and type of stimulus on a bus could potentially cause participants to become easily distressed.

Potential barriers to using a bus existed across different stages of the journey. Successfully planning and embarking on a bus journey required the integration of various pieces of visual, audio and written information which was challenging for many participants and time consuming, especially when these journeys were to new destinations or had not been taken for some time. In particular, those with autism / Asperger's or mental health impairments described having to check every element of a journey when planning, in order to reduce potential anxiety on the journey itself or reduce the need for interactions with others. One participant with Asperger's avoided using the bus completely as it was perceived as the most stressful of transport modes. Other participants admitted they would sometimes not get on a bus if they were very crowded. Some would wait for the next bus to turn up, whilst others preferred to walk if their destination was not far away. Participants also avoided overcrowded buses in peak hours as proximity to passengers was distressing. Some participants wanted to be near exit doors to allow them the option of getting off the bus early if they felt anxious and this was more difficult when the bus was crowded.

Participants often felt anxiety when getting on buses and on the journey itself. Many discussed wanting to confirm that they were on the correct bus, even where this information was already shown on the front of the bus. Participants also wanted to know what the fare was going to be if they were taking a bus at a different time of day or day of the week, and if they were going to a new destination, some wanted the driver to confirm when they had reached the correct stop.

Interactions with the driver required having to ask questions and participants with autism/ Asperger/s learning disabilities found this difficult as their impairment impacted their verbal fluency. In addition, drawing attention to themselves made them feel embarrassed and anxious about how they might be treated. Some had experienced bus drivers who were not considerate towards them and wanted to avoid the potential for this to happen again.

There were mixed perceptions of bus drivers' willingness or ability to lower ramps on buses. One participant with a mobility issue had experienced a spasm in his back when getting on and off a bus because the driver had not lowered the ramp for him. He had also tripped and fallen while trying to get to his seat after the bus pulled away. This participant also experienced difficulties using steps on trains.

Whilst bus stations may have offered more information and access to staff, participants generally disliked the busy and noisy environment, and some avoided using them for this reason and would get off the bus a stop early to avoid entering the bus station.

For those using buses frequently, many participants spoke about feeling anxiety if a bus was seriously delayed, or if it didn't arrive. It appeared that there was a general lack of real-time travel information across locations, and the lack of consistency between timetabling information on bus websites, existing services, information at bus stops or apps meant that planning was perceived to be fraught with error. Anxiety could be experienced by arriving at a bus stop with little information about the services stopping there, and an inability to confirm if they were at the correct bus stop.

Although some felt the need to add in extra journey time in case their bus was late or did not turn up, participants also spoke of occasions on which this had led to panic attacks and uncontrollable worrying. This was exacerbated by travelling on their own, the fear of unwanted attention from others, or behaviours brought on by their impairment when in an anxious state.

"One of the biggest things for an autistic person is the unknown, if I knew from start to finish how my journey is going to be...if I knew where the bus station was and roughly where the buses go, but there are too many variables and it's so frustrating"

Autism, Norfolk

"It's hard to find information about the buses, even if you find a timetable you can't understand it – well I don't!"

Mental health impairment, Manchester

"If I have to take a bus I have nightmares for a week. The more rural you are the worse it is...it's very inconsistent [when the buses turn up] ...prices are always changing...it's very overwhelming I don't like it at all...I'm good with technology, I'm good with computers but I struggle to find one [timetable] for a bus"

Autism, Norfolk

On bus journeys participants mentioned the lack of any real-time travel information or visual route information on board the bus. Participants with autism/ Asperger's and some with mental health impairments found visual information easier to process and used Google maps to help them stay connected to the current location of the bus on its route. This happened more often when using a new bus, going to a new location or where journey disruptions occurred. Participants with learning disabilities were not as confident using smartphones and relied on their learnings from travel training to help them with navigation difficulties.

Participants experienced real anxiety where journey disruptions occurred or where they were unsure which bus stop was closest to their destination. In these situations, additional anxiety may be experienced if they needed to ask a question of bus drivers or other passengers. Participants with autism/ Asperger's described feeling embarrassed or being perceived as 'stupid' by others if they asked something obvious. Several participants felt that bus drivers were not very helpful in these situations or ignored their requests to be told when they reached a certain bus stop.

"I'd like bus drivers to have more understanding of passengers who have difficulties, like they know where they want to go but not where to get off. They don't have any patience, they tut-tut and look at you and then the clock"

Learning disability and brain injury, Manchester

Many bus users commented on a lack of comfort on their journey which was attributed to a range of factors. Participants with autism/ Asperger's and those with severe mental health impairments particularly disliked the noise from the bus itself and surrounding traffic, and often wore earphones to keep out the noise of traffic or other passengers on the bus.

Several felt that bus drivers often pulled away from bus stops before they had a chance to sit down or drove too fast when approaching bus stops. Others felt that buses were generally too crowded and found sitting or standing near other passengers made them feel awkward and uncomfortable.

"They have the first four seats for the elderly and the disabled (...) but sometimes it's hard to get a seat and people just think like you're young, there's nothing wrong with you. When the bus is busy, it's hard sometimes because I just need to find somewhere to lean"

Physical and mental health impairments, Reading

"If I don't feel right or there are too many people there I'll get off at the next stop and walk the rest of the way. They pack people in like sheep in barn. Sometimes it's too crowded and the bus driver let's too many people on - there's a sign saying how many are allowed but they ignore it"

Learning disability, Manchester

One rural participant who either used a wheelchair or walking stick was forced to take a bus if either her family member or friend was not available to drive her, or a taxi was not available at the time she needed it. Whilst she praised the availability of buses with bus ramps and the helpfulness of bus drivers in this regard, this participant felt unsafe during the journey, despite a brake on her wheelchair, and felt there was a potential for her wheelchair to move around the bus if it travelled at speed. She therefore felt that seat belts should be provided on buses for restraining wheelchairs.

"When the bus is really busy, I won't get on or if it gets busy, I get off earlier cos I feel like I can't breathe. It's anywhere there are loads of people and you're like sardines"

Anxiety and depression, Manchester

Travelling by train

Motivations	Potential barriers
<ul style="list-style-type: none"> • Relatively straight forward to plan in advance/book tickets/access prices • Train journey is more comfortable than buses 	<ul style="list-style-type: none"> • Some lack of self-confidence with buying ticket online • If travelling alone, often involves using another transport mode to reach station which increases processing required / mobility issues / anxiety • Busy and noisy environment overwhelming in large stations • Some aspects of station design including mirrors / materials / colours/ signs misinterpreted by dementia participant • Barriers to accessibility for older participants with mobility issues - lifts/ escalators • Mixed staff visibility e.g. on platforms/ at smaller or unstaffed stations therefore more difficult to confirm if in correct place/ obtain directions for interchange • Mixed levels of confidence to approach staff to ask for help • Announcements at station not always clearly understood • Anxiety if need to move platforms • Announcements on the train not always clearly understood • Low visibility of staff on train to help if delays/ disruption/ confirm reached correct interchange • Some toilets claustrophobic

Many participants reported using trains but less frequently than other modes. Trips usually included leisure trips to visit friends and family, visiting cities such as London for sightseeing, and other destinations for holidays. Trips were made both in and out of school holidays. Some living in the commuter towns of Watford and Reading took the train to work or on business trips. Those using trains to commute tended to travel independently whilst others taking leisure trips tended to be accompanied by their carer, a family member or their children. Older participants with mobility issues avoided taking the train because of difficulties using lifts and escalators. Some participants with mobility issues were aware of Passenger Assistance, others were not.

When travelling alone, participants tended to be more motivated to use trains on journeys involving only a few stops, or direct routes. Whilst the trainline.com provided comprehensive journey information and real time updates, participants felt that longer journeys involving changes would make them feel anxious and there was a greater potential for delays or disruptions. Previous experience of disruptions had involved some having to phone family for help because of their reluctance to approach staff or lack of visibility of staff on board the train.

Key issues for participants when using trains involved having to manage the busy and noisy environments of railway stations. These exacerbated anxiety and waiting rooms were used as quiet spaces although were perceived by some as cold and uncomfortable.

“Reading station is overwhelming it used to be nice and small and compact, it’s horrible, I hate it when it gets really busy, it’s scary because there’s so many people, and they’re all coming at you, and it’s such a big place, and they just walk into you, they just don’t care. I get confused about what is off peak or on peak so I will always just try and get the cheapest train ticket on the day of travel rather than buying it online in advance”

Mental health and physical impairments, Reading

One participant with dementia experienced issues interpreting signs, symbols and colours. Whilst she always travelled with her husband, she became disorientated by some aspects of rail stations. When using the toilet at a large station she had become disorientated by the presence of mirrors and had to be guided out by a staff member.

“We once travelled to Brighton through London. When we got to Victoria there were these swirly patterns on the floor. All very nice in terms of décor. But she said they seemed to be moving. Things like black doormats when you go into a food store by the automatic doors- to her they look like a hole. If they were brown it would be much better. Don’t put black doormats inside doors”

Carer of participant with dementia, Manchester

Issues for participants with autism/ Asperger’s, learning disabilities and some mental health impairments related to difficulties processing verbal information such as station announcements and instructions given by staff regarding platform or time changes. There was a general reluctance to approach staff for help and a perception that staff were not always easy to spot.

“Once they said there’s been a platform alteration and I didn’t know what alteration meant at first. Then they said go to a different platform. I got stressed and thought I was going to miss the train”

Autism, Manchester

“Waiting at a platform causes me anxiety. Multiple platforms make things very complicated. It’s just very loud to the point that I can’t see. I need to have my headphones on or I will get flustered. I find it hard to find a member of staff. I stand there looking flustered hoping that someone will help. Nine times out of ten I will ask if I’m on the right platform and I will just approach anyone for that, but I do prefer to travel on a train with someone”

Autism/ ADHD, Norfolk

On regular and frequent journeys, or where travelling with someone else, most felt that a train journey was comfortable, spacious and relatively relaxing, especially when compared with buses. This feeling helped participants to stop thinking anxious thoughts. Several also spoke about wearing earphones to keep unwanted noise out. Comments were made about low staff visibility on trains and when participants did need help they either sought information from Google maps or trainline.com if possible. As a last resort they spoke to other passengers or phoned family for reassurance that they were getting off in the right place if making an interchange or reaching their destination.

“I used to feel more confident on train as it’s just a straight run not like the stopping and starting on the bus”

Learning disability, Manchester

One participant with mental health impairments felt that toilets on older trains were too small and potentially induced feelings of claustrophobia because of lack of space.

Travelling by tram

In summary, for those using trams, there were many more motivations than barriers

Motivations	Potential barriers
<ul style="list-style-type: none"> • Good accessibility – step-free access and many doors • Audio-visual information on board • Fixed route so no detours or disruptions • More spacious and comfortable than trains • More punctual and reliable than trains 	<ul style="list-style-type: none"> • Limited routes

In Manchester, participants' experiences of using the tram were generally positive, compared to using other types of transport. When available, trams were preferred over the bus as they overcame two of the main barriers to travelling by bus - good accessibility and on-board information. They were also free from detours or disruptions and services were more reliable and punctual than buses, which resulted in less anxiety for participants.

“They’re ideal really. I’ve never seen a tram be late. They’re easier than buses because there’s lots of doors to get out if there’s a problem. The timetables are easier to understand, and they are more on time than the train.

Asperger’s and anxiety, Manchester

Timetables and information at tram stops and on-board were comprehensive and offered audio visual information via easy to read maps; a factor that deterred many from taking the bus.

In terms of the design and infrastructure, the step-free access was valued by older participants or those with mobility issues or using prams.

“We find the tram very good because it’s all flat. There are no steps and very accessible. Otherwise we use the car because it is easier.”

Carer for participant with dementia, Manchester

Trams were also thought to be more spacious than buses or train, and easier to enter and exit because of the number of doors available.

6 Potential interventions to improve transport access

6 Discussion of interventions

Participants were asked to identify whether there was anything that might help improve their journey experiences and encourage greater use of different types of transport. This section discusses the ideas which participants felt could minimise the impact of their impairments whilst travelling. Interventions are suggested for modes which caused the most issues for participants and broken down by journey stage if applicable. Overall, navigation aids such as Google maps, already used by many participants, were perceived to help with journey planning and travelling. Tailoring journey apps to better meet the needs of those with non-visible impairments could potentially motivate greater use of public transport.

A summary table of interventions suggested for each transport mode is shown below and these suggestions are expanded in the sections beneath the table:

Interventions to encourage greater use of cars	<ul style="list-style-type: none"> • Navigation aids/ apps to suggest quieter times of day to travel or alternatives to fastest route • Ability to identify and pre-book parking spaces if using Blue badge scheme
Interventions to encourage greater use of taxis	<ul style="list-style-type: none"> • Ability to book taxis online, via text or app • Confirmation and reminder taxi that is on its way
Interventions to encourage greater use of buses	<ul style="list-style-type: none"> • Better coordination of timetables across bus company websites • Simplified timetabling information on websites • Journey planners (apps or on bus websites) which includes fare information and ability to buy tickets in advance, and sends reminder text about bus waiting times • Real time information about waiting times at bus stops • Map on bus to show overall route, current bus position, and real-time information about time taken to next stop, and any delays/ disruptions on route • Non-cash payment system for bus users • Bus drivers to receive training on non-visible disabilities • Assistance cards for bus users to identify self and needs to driver • Improved safety via safety belts for wheelchair users, more seats to avoid standing, and arm rests on aisle seats • More direct buses stopping at fewer stops to reduce journey time
Interventions to encourage greater use of trains	<ul style="list-style-type: none"> • Easily accessible safe/quiet space in stations • Staff who are trained to deal with people who have non-visible disabilities • Greater staff visibility on platforms • More comprehensive visual information about journey route and timings/ notification of delays/disruptions on board trains • Signs on train exterior showing carriages with toilets

Interventions to encourage greater use of cars

Participants did not have any specific suggestions for improving their information processing issues when driving, other than for navigation aids to provide suggestions for the quieter times of day to travel or alternatives to the fastest route, such as the least busy route.

A key issue for drivers was being able to identify accessible parking spaces. This was most important for those driving themselves or family members to hospital appointments, or when driving to stations or airports. Whilst a few mentioned the Blue Badge scheme this tended to be older participants with mobility issues. Users felt that this scheme could be improved by being able to identify and pre-book spaces where possible to provide more certainty about the journey and reduce the stress associated with being able to access buildings easily- a reason why participants often used taxis as an alternative to cars.

Interventions to encourage greater use of taxis

The ability to book taxis online or via text was perceived to help those who found it difficult to speak to someone on the phone. For those living rurally with more limited access to taxis later in the day or evening, or those with memory issues, the ability to pre-book a taxi would be helpful especially if a confirmation and reminder was sent to users when the taxi was on its way.

Interventions to encourage greater use of buses

Interventions suggested to motivate greater confidence when using buses involved the following journey stages:

Bus journey planning

Participants wanted better coordination across bus company websites, and for each website to offer some form of journey planner which aggregated all local bus company timetables and offered up to date timetabling and pricing information for a complete journey. In addition, some bus users wanted a simplified journey planner app allowing them to enter key journey information, together with the ability to buy a ticket in advance and receive a reminder text about waiting times. This would allow participants to make more informed decisions about whether the bus offered a viable alternative to taking a car. Knowing fare information in advance would also minimise anxiety about ability to take a bus and minimise the need for communication with drivers when getting on the bus.

Carers of participants with learning disabilities wanted a very simple timetable which their family members could use easily at home. Participants' confidence with using technology and motivation to use technology was limited and some carers reported difficulties contacting their loved ones on their mobile phones whilst they were travelling. Family members felt that if participants received a reminder text from bus companies about bus waiting times this could be referred to when needed and would assist anyone with memory issues, not just those with learning disabilities.

Waiting for buses

For those accessing information about buses whilst out and about, a key concern was lack of access to reliable, up to date information about waiting times at bus stops, especially for those who were not accessing this type of information on Google maps. Some participants who had travelled to large cities such as London or Edinburgh were aware that real time information could be provided at bus stops using dot matrix boards. They therefore felt this type of service in their home location would help minimise uncertainty and contribute to more informed decision making, enabling participants to

choose whether to wait for a bus or take an available alternative such as walking or taxi. This information would also help those who had experienced bullying or name calling when waiting at bus stops, who felt that if they knew how long they would have to wait for a bus they could make more informed decisions about whether to put up with the unwanted attention.

In Reading, some bus users appreciated the bus app and in other locations, participants who were able to text a local number to find out the waiting time suggested that a simple app as an alternative to this would offer more flexibility.

Getting on buses

Real time information at bus stops would help participants to confirm that they were getting on the right bus as well as inform them about waiting times. As a 'double check', to confirm that the participant was on the correct bus, or to avoid having to ask drivers, a small number of participants suggested a map on the bus for the participant to refer to, and if necessary show the driver. This would enable them to confirm the bus route and/ or the stop they wanted to get off if they felt confident enough to ask questions.

As described, travelling with someone else when possible was often preferred. Some participants had been provided with a Companion Bus Pass and felt this service made them feel more confident as they could rely on their companion to converse with the driver on their behalf.

Other participants wanted to avoid the need to pay their fare with cash and suggested a similar system to Oyster cards used in London. They felt that being able to load a card with money in advance would enable them to be more spontaneous about taking buses and reduce the need to interact with drivers.

Overall, many wanted bus drivers to receive better training so they would be more aware of participants' potential communication, or other issues, and be considerate towards their needs. Some participants felt that if they could identify themselves to the driver as someone with a non-visible disability, this may help. Not all were willing to be identified in this way, but some were aware of the existence of 'assistance cards' summarising issues or needs, and felt this could help them if shown to staff. One participant mentioned that the National Autistic Society offered assistance cards and thought that a charge applied, which was felt to be inappropriate. Another participant had been offered something similar to an assistance card and thought this had helped to raise staff awareness and provide help where required. They also felt this could be adopted by other transport modes.

“When we have used Stansted airport we have been given a lanyard or bracelet and they use these to help people know that we have a hidden disability, it helps them fast track queue you as standing in line is difficult for our family, my wife has fibromyalgia and my daughter has autism, so it really helps”

Autism, Norfolk

The journey experience

It was very important for participants to be confident that they knew their current location whilst on the bus and many used Google maps to track this. Ideally, participants wanted a map showing the bus route which indicated where the bus was on the route, and showed landmarks, similar to using Google maps. If this could also show the time taken to reach their destination and provide alerts about delays or disruption to the route taken, either from the driver or through real-time information, this would also be informative. Those travelling in Manchester found the system used on trams was informative and wanted this to be adopted by buses.

Participants felt unsafe if the journey involved fast speeds or instability, for example when manoeuvring roundabouts. This was of particular concern for participants with mobility issues. One participant who sometimes needed to use a wheelchair when travelling felt that seat belts would make her feel more safe and secure than just applying the wheelchair brake. Another participant wanted more seats on buses to avoid the potential for falling over. Other bus users felt that arm rests on aisle seats would make them feel more secure and provide some boundary between them and other passengers.

Several participants wanted more direct buses with fewer stops to reduce the length of a journey, or a distraction in the form of a TV to take their mind off the journey.

Interventions to encourage greater use of trains

At the station

Many participants found larger and / or unknown stations more difficult to manage and could be overwhelmed by crowds. Some wanted to be able to access a safe or quiet space whilst waiting for a train but did not know if these were available. It was difficult for participants to consider approaching staff if they did not feel verbally fluent and they would feel anxious or embarrassed if this were the case. Participants suggested that if staff were trained to communicate sensitively with people with non-visible disabilities then they would be more open to approaching them and would feel more confident if staff wore an easily recognisable jacket or badge indicating their skills.

Those using unstaffed stations wanted some way of informing train guards of faulty ticket machines, so they were not penalised if boarding the train without a ticket.

Waiting for trains

Participants encountered difficulties processing verbal information such as station announcements and instructions given by staff on platforms. For this reason, visual information, such as information boards showing platforms, destination and route information, was preferred where possible.

On the platform, train users wanted to confirm they were in the right place. Staff visibility was perceived as variable but participants were also reluctant to approach staff. Those with mobility issues or using prams/ buggies who had experienced anxiety when doors closed too quickly, believed they would feel more confident getting on trains if there were more staff available on platforms to help.

"If there was someone who was walking round with a 'can I help you badge'...then that gives you that bit of reassurance without feeling stupid"

Mental health impairment, Watford

One participant felt strongly that staff could benefit from an advertising campaign encouraging those with mental health impairments to speak to staff.

"If I felt really bad on public transport, I would want to talk to someone. [The stigma of mental illness has been lessened so] I feel more inclined now to speak to someone than 30 years ago"

Mental health impairment, Manchester

The train journey

Whilst on the train participants wanted more comprehensive visual information about the route, with similar comments as for buses. Many reported using earphones to keep out unwanted noise and distract themselves from anxious thoughts and were therefore liable to miss verbal announcements from staff. Whilst some kept up to date about the journey by accessing trainline.com or google maps, visual information would be an additional source of information and provide detail they could rely on.

One participant felt that trains should have a sign on the outside to notify which carriages have toilets.

7 Summary and conclusions

7 Summary and conclusions

What are the current issues and what can help?

- Impairments can impact the ability to process and retain information when planning travel and making journeys. Technology, such as Google maps, helps confident technology users at the planning stage by providing real time information to help reduce uncertainty around waiting times, reduce the cognitive load and inform decision making by planning routes
- Technology can also help confident users when using transport, for example journey planners such as Google maps, Waze and train company websites provide up to date visual information. Technology can also help to reduce uncertainty when journeys change or disruptions are experienced
- However, those who are not as confident using technology use other less efficient sources which do not minimise the effects of their impairments. Many therefore wanted to be able to access live information to help them plan more efficiently, increase confidence and enable informed decision making about whether to use transport. For example, using buses for short journeys rather than driving, and potentially planning longer journeys
- Impairments may affect an individual's ability to communicate easily and effectively. Key barriers are experienced when communicating with staff, in particular on buses, where drivers are generally perceived as unhelpful and inconsiderate towards passenger needs
- There is openness among transport users to being identified as having a non-visible disability and this was perceived as a way for staff to understand the impact of impairments more easily and for trained staff to provide more efficient communication with passengers. Assistance cards were praised by those who were aware of them. Others suggested this as a way to identify non-visible impairments
- A barrier to taking buses is lack of clarity about fare pricing. Increasing clarity could provide greater motivation to use buses more frequently
- Adopting a cashless payment system on buses may also promote greater frequency of bus journeys as this would remove the uncertainty about the cost of a journey and reduce the fear associated with communicating with others
- Passenger safety on buses and in taxis was an issue with some calling for more safety measures such as safety belts on buses for wheelchair users
- At the time this research was conducted, the Blue Badge scheme had not yet been extended to those with non-visible disabilities. Drivers in our research who did not have mobility issues felt that access to the Blue Badge scheme may encourage them to use cars more often as this would provide greater certainty about reaching their destination on time, especially if there is an opportunity to pre-book parking spaces
- Companion bus passes, where they are provided by local authorities, were praised by those who use them and if adopted more widely could allow greater use of buses by those who would feel more confident travelling with someone

Future research should aim to include ethnographic research observing participants using different transport modes to uncover additional barriers or insights related to participants' experiences; provide a more objective view of the advantages and disadvantages of current interventions used and generate ideas for future interventions. Research should focus on using local buses in particular as these could be used more widely for short, regular, frequent trips.

8 Appendices

DfT Accessibility Interventions discussion guide.v3
1.5 hour depth interviews

Two key research questions:

- How do people with cognitive, behavioural and mental health impairments experience travel in their day to day lives?
- What interventions could help to improve journeys and encourage more travel?

Use of guide

The guide outlines key areas of topic guide coverage and includes prompts and probes, rather than fully-formed questions. It is designed to be used **flexibly** and to allow researchers to be responsive to issues raised by participants.

It may not be possible to cover all of the issues outlined in this topic guide with every participant. Everyone should be allowed to consider each question at their **own pace** and the discussion should be responsive to the issues they raise. The order of questions may also vary, depending on which topics are considered most important to the participant.

Length of discussions will vary dependent on how much the participant has to say, how long they require to process the question/ their response and whether a carer/ relative or friend is present.

We will use **showcards** to remind participants about the topic of conversation and provide a visual stimulus and **rotate the question areas** so we achieve coverage of all.

Role of the carer: As far as possible please focus ensure that the discussion focuses on the participant– we are keen to hear their views. If a carer is present, and the participant is uncomfortable with a particular issue, we are happy for the carer to respond and view this as their view on how they think an issue affects the participant; rather than answering for the participant.

Section 1). Introductions and Warm up

5 mins

- Thank participant(s) for taking part in the study
- Introduce self
- **Consent form:** ask following questions then take participant through consent form to ensure they are aware of what is involved and are happy to proceed
 - Can I ask why you wanted to take part?
 - What will be the benefits for you of taking part?
 - Do you have any concerns about taking part?
- **Ipsos MORI** is a research agency that conducts research for the government. We are independent which means you can be open and honest in what you tell us
- **Qualitative research:** this means there are no right or wrong answers, we want to know your opinions and views.
- **Length of interview :**we would like to cover a range of topics with you. We can take breaks whenever you need and we will talk to you for as long as you are able, up to a maximum of 1.5 hours.
- **Purpose of this research:** we would like to understand your experiences of using different types of transport. We are working on behalf of the Department for Transport who would like to better understand your specific experiences and specifically if there any issues related to your impairment that affect your journey experiences. We would also like to see what might encourage you to use different types of transport more frequently in the future and if there are any ideas you have that would make this easier for you
- **Confidentiality:** reassure that information you provide in this discussion will not be linked back to individuals, and no names of individuals will be included in any reporting.
- **Permission to digitally record:** we will use this recording to ensure we accurately capture your views. The recording will only be listened to by me and my colleagues working on this research. It will be deleted after the research is completed.
- **GDPR added consent (once recorder is on):** Your participation in this research is voluntary. Ipsos MORI would like your consent to record this research. You can withdraw your consent for your data to be used at any point before, during or after the interview. Can I check you are happy to proceed?

- **Ask participants to introduce themselves:** first name, age, marital and family status, working or retired, what you do in your spare time

Your day to day life nowadays

5 minutes

- Can you tell me a little bit about your day to day life?
- What is your daily and weekly routine like?
- How has this changed in the last 5 years?
- What do you enjoy doing? What makes you most happy and relaxed?
- What do you like about living in (use location)
- Are there any things that worry you?
- Would you mind telling me how long you have been living with your impairment and how it might affect your day to day life?
 - Establish if impairment from birth or acquired in adult/ later life
 - Have you had to make any changes to your life over the last 5 years as a result of your impairment.
 - Probe sensitively on:
 - Changes to their routines
 - Changes to where they live
 - Additions/ changes to amount or type of support received
 - How have these changes made you feel? Probe sensitively on:
 - Loss of self-confidence?
 - Loss of independence?
 - Other?
- *Moderator: ask participant if they are OK to continue or if they would like a break*

Travel attitudes and behaviour

10 mins

- Do you get out and about very much? Probe on:
 - Frequency of travelling nowadays
 - how this has changed over last 5 years
- Tell me a little bit about the types of journeys you make: Probe on: work; study; hospital visits; support groups; social visits; other
- Can you tell me
 - How often you make these different types of journeys?
 - How long the journeys are usually?
- What, if any types of transport do you use when you are out and about? Probe on:
 - Which types of public transport are available in their area
 - Which of those types of public transport used
 - Which types of private transport/ other used (inc.walking/cycling/wheelchair)
- How frequently do you use the different types of transport you have mentioned?
- How do you feel about using different types of transport?
 - Explore spontaneous likes and dislikes of using transport modes
 - *Moderator: Use Showcard A to help participant identify relevant emotions*
- What do you most like about using different types of transport?
 - Explore detail for each type of transport mentioned
- What sort of problems do you have when using different types of transport?
 - Explore detail for each type of transport mentioned
 - Probe on problems specific to their impairment
 - Probe on the extent of the problems
- *Moderator: write list of likes/ problems on A3 paper to use as an aide memoire for participant to refer back to through interview*
- *Moderator: ask participant if they are OK to continue or if they would like a break*

Planning journeys

5 mins

- Can you tell me if you do any planning when you make a journey?
- If yes, probe on what sort of planning they do and how they do this:
 - Finding out bus/ train times

- Finding out routes
- Buying tickets in advance
- Booking passenger assistance
- Looking for step free routes
- Looking for routes that feel safe
- Other
- How do you feel about planning journeys? (*Use Showcard A if participant would find this useful*)
 - Chore?
 - Like to be prepared?
 - Necessary because of issues related to their impairment?
- How easy/ difficult is to plan your journeys? Probe on what things make planning easy/ difficult
 - Generally
 - Sourcing information
 - Sourcing assistance
- Do you tend to use any websites to find out information or to help you with planning your journeys?
 - If yes, how does going online make it easier/ difficult?
 - If no, what do you not like about using technology for travel?
 - What sort of information would be useful
 - How could websites be changed to meet your needs
 - If no, what sources do you use e.g. help from friends and family
 - Do you use websites and go online in your day to day life? Why? For what sort of things?
 - Do you use apps for anything? What sort of things do you use apps for and why?

Your journey experiences

40 mins

Moderator: Use SHOWCARD A (facial emotions) to help participant identify their feelings towards using transport and other showcards to help participant if they need visual stimulus for different journey stages

- Ask participant to describe their last journey and what the experience was like. If not mentioned, probe:
 - Journey purpose
 - Destination
 - Type of transport used
- How typical was this journey compared others they have made recently?
- What types of transport do they prefer to use and reasons why?
- What would an *ideal* journey be like?
- *Moderator* to choose a transport mode that seems most relevant e.g. most often used, most challenging to use, mode the participant wants to use more but barriers prevent use etc.
- Ensure at least one other mode discussed in interview, covering as time allows.
- *Moderator*: Whilst we aim to cover a range of transport modes across interviews– focus on modes which have potential to provide most insight
- For each type of transport used, explore the following questions. Ask participant if they need to take a break after discussing each mode used
- *Moderator*: I would now like to explore some specific things about different types of transport with you to see how they affect your experience of travelling.
- *Moderator*: important to tailor questions to different transport modes. If participant uses cars some of the following stages may therefore not be relevant
- **Making your way to use the type of transport**
 - What does this involve? e.g. walking, taxi, car
 - What words would you use to describe how you feel when you are making your way towards using the main type of transport?
- **Arriving at the transport mode** eg bus stop/ bus or train station / getting in the taxi/ car
 - What words would you use to describe how you feel when you are about to use the transport?
 - How do you make sure you are in the right place? What do you use to help you?
 - How would you describe the general environment when you arrive at stations?
 - How do you feel about the noise levels at stations?
 - How do you feel about other passengers at stations?
 - How do you feel about being able to find or use facilities such as toilets whilst at a station?
 - How do you feel about using ticketing machines or manned ticket offices?

- How do you feel generally about interacting with staff at stations?
 - Does staff attitude towards you influence how you feel at all?
 - Generally, how much do you feel staff are aware of/ trained in disability awareness?
 - How do you feel staff are like when you are with your carer?
- Do any of the things we have been talking about differ at any time? eg do you feel the same every time you travel or does it depend on the particular time of day or day of the week, or if you are on your own or travelling with someone else?
 - Have you had experience of unmanned stations and if so, how does this make you feel?
- **Getting on the transport**
 - How do you feel when you are getting on the bus/train or in the taxi/car?
 - How do you make sure you are getting on the right bus/train/taxi?
 - What information is helpful to you?
 - What makes this part of the journey easier/ more difficult for you?
 - Probe attitude of drivers or other staff they come into contact with
 - Probe attitude of staff who are assisting with Passenger Assistance
 - Probe how it feels to be travelling with other passengers
 - Probe how they would describe what it feels like being on a bus/ train/ in a taxi/car
- **The journey**
 - How do you feel on the journey when you are travelling?
 - What words would you use to describe this part of the journey? Why?
 - What sort of things make the journey easier/ more difficult for you?
 - What type of things make you feel confident when you are on the journey itself?
 - Do you ever use a mobile phone to help you in any way? Probe on how/ when mobile phones used and benefits/ disadvantages
 - Are there times when you feel anxious or less confident on the journey than you would like?
 - What sort of information do you use to help you on the journey?
 - If so, what types of things make you feel anxious or less confident than you would like?
 - Probe noise levels, other passengers, staff, vehicle design, general comfort, signage and other communication
- **Reaching your destination**
 - What do you use to help you make sure you have reached your destination?
 - When the destination is somewhere other than home, how do you feel when you arrive?
 - What type of things make you feel more/ less confident at this point in the journey? Why?
- **Overall**
 - Which stage of each journey makes you feel most prepared and confident? Why?
 - Which stage of each journey makes you feel least prepared and confident? Why?
 - Which type of transport do you feel most/ least comfortable using? Why?
 - Which types of transport are the most / least difficult to use/ why?
 - What would be the one big thing you would like to change that would allow you to feel more prepared and confident about using transport more often? Why?

The future- exploring interventions

20 mins

Moderator: Thank you for the feedback you have provided so far. I now want to talk to you about how your journey experiences might be improved in the future. I've got some ideas to share with you, but first I wanted to know what you think might help you to have a better experience when you use different types of transport in the future?

- What type of changes would make the biggest difference to you when you are using public or private transport? Explore fully any spontaneous ideas.
- Let us think about the types of transport that you said you find difficult to use
- Probe on ways in which the following might help encourage greater use of transport modes that are used less often
 - Changes to transport infrastructure
 - physical environment including
 - ease of navigation
 - general comfort levels in different environments
 - ability to easily/ confidently obtain tickets

- facilities in stations such as seating/ toilets
 - Vehicle design and comfort
 - Clarity of signage and communications
 - Staff attitude/ knowledge/ skills/ ability to provide assistance
- In what ways do you think technology might help you feel more prepared or confident about using transport?
 - Spontaneous
 - Do you think it could make planning your journey easier in any way? How?
 - Do you think it could make your journey experience easier in any way? How?
 - Do you think it could give you more confidence when planning or making a journey? How?
- If technology could improve your journey experience do you think you might use it?
 - Do you use any websites or apps to help with your current journeys?
- Which of these ideas would you like to know more about? Why? How do you think they would help you in the future?
- Have any of these ideas made you think of other ways in which your journey experience could be improved in future?

Wrap-up**5 mins**

- We're coming towards the end of our chat now, so is there anything we haven't discussed which you would like to add?
- What is the most important thing for us to tell DfT about the ways to help you use transport more often in the future?
- Thank participant and close interview
- Ensure incentive form signed (carer and participant)
- Hand information sheet to participant and explain its purpose- this is what we will do with the information you have given us. Are you still happy for us to use this information? Here are some places you can go for more information.