Inclusive Transport Strategy Evaluation

Understanding disabled people's lived experiences of the transport network

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Glossary of terms

- **Assistance dog** – a dog which is specially trained to support the needs of people with disabilities and medical conditions.
- **Blue Badge** – a parking permit valid for people with disabilities, allowing them to park in designated disabled parking bays.
- **Changing Places** – standard accessible toilets do not meet the needs of all disabled people. Changing Places are toilets that include additional space to accommodate the need for carers and specialist equipment such as changing benches and hoists.
- **Congenital health condition** – a health condition that is present from birth, rather than being acquired later in life.
- **Disability** – a person is defined as disabled if they have a physical or mental health condition or impairment, lasting or expected to last 12 months or more, which has an impact on their ability to carry out day-to-day activities (as per the Equality Act 2010).
- **Fluctuating health condition** – characterised by symptoms that are always present, but which vary in severity and can suddenly intensify, for example during a 'flare-up'.
- **Inclusive Transport Strategy** – a governmental strategy aimed at creating a transport system which offers equal access to disabled passengers by 2030.
- **Logic Model** – a logic model is a description of a chain of causes and effects, showing how the actions involved in an intervention or policy are expected to lead to the intended outcomes. Logic models are typically presented in graphical form.
- **Motability scheme** – a scheme which enables eligible disabled individuals to exchange their mobility allowance to lease a new car, wheelchair accessible vehicle or powered wheelchair.
- **Passenger Assist** – a service for older and disabled rail passengers, which can involve helping passengers on and off trains, reserving wheelchair spaces and seats, provision of information, and more general assistance.
- **Priority seating** – seating on public transport which is designated for disabled people, older people and those who are pregnant or less able to stand. This is often more spacious than standard seating and is closer to the entrance/exit.
- **Recurring health condition** – characterised by symptoms that come and go, with periods where the individual may not be affected at all.
- **Sunflower lanyard** – also known as the Hidden Disabilities Sunflower, the sunflower lanyard indicates to people around the wearer that they may need some extra support or assistance.
- **Transport hubs** and **interchange hubs** – we use the term transport hub to refer to any single location from which passengers can access at least one mode of public transport, such as a bus stop, train station, taxi rank or airport. We use the term interchange hub to refer to transport hubs from which at least two modes of transport can be accessed, typically when switching from one mode of transport to another during a single journey.
- **Trigger** – we use the term trigger to refer to anything within a participant's travelling environment that prompted an involuntary, adverse psychological reaction, as a function of the way that the trigger interacted with their mental health condition. When triggered, reactions included feeling an overwhelming sense of anxiety or stress, a panic attack or a flashback.

1 Executive summary

The Inclusive Transport Strategy (ITS): Achieving Equal Access for Disabled People, published in July 2018, is an ambitious programme of work which aims to create a transport system that offers equal access for disabled passengers by 2030. At its core, the ITS has an ambition for disabled people to have the same access to transport as everyone else, and to be able to **travel confidently**, **easily** and **without extra cost**.

In January 2022, the Department for Transport (DfT) published the baseline report of the ITS evaluation, based on the first wave of data collection. The baseline report presented the findings from multiple strands of primary research, including quantitative surveys and qualitative interviews with disabled people and transport stakeholders.

This report is also based on the first wave of data collection, but draws exclusively on qualitative interviews with disabled people. While this report does address some of the same themes as the baseline report, it aims to explore disabled people's **lived experience** by describing their views and experiences of public transport in rich detail and in their own terms, by extensive use of individual pen portraits, and by allowing key themes to emerge iteratively from the data. In particular, the report explores the range of positive and negative experiences disabled people had when travelling, and how disabled people made decisions about whether and how to travel.

1.1 Key findings

Managing health conditions and impairments

The exact nature of disabled people's health conditions and impairments was, of course, a crucial factor in their decision making and in their travel experiences. The symptoms disabled people experienced informed whether they chose to travel, at what times, for how long, by which modes and under what circumstances. A key factor was whether the symptoms associated with a condition or impairment were *constant and predictable*, or whether they *varied significantly or unpredictably*. Periods in which symptoms were worse or more difficult to manage often led to the decision not to travel at all, or to travel by different modes (such as by taxi), or under very narrow conditions (for example, when the network was not busy).

For some disabled people, specific features of journeys had the potential to directly trigger a worsening of symptoms, and needed to be avoided. Most obviously, not having access to a seat could worsen pain and fatigue, as could a need to walk long distances. Transport temperature that was too hot, or too cold, could also worsen a range of symptoms. For disabled people with mental health conditions such as Post-Traumatic Stress Disorder, travel decisions were made in order to avoid triggers, such as having to travel at night, or for some women, being alone on public transport with men.

The need for certainty about journeys

It was typical for disabled people to need high levels of certainty about their journeys. This could mean being sure that they would be on time for their bus, train or flight, that their journey would not be delayed or cancelled, that they would be able to get a seat, that the expected accessibility adjustments would be available and functioning, that they would have the facilities required to manage their symptoms, or that staff assistance would be provided and meet their needs.

Disabled people needed these high levels of certainty because the consequences of unplanned changes could be severe. If journeys took longer than planned, disabled people could be left in significant pain, or the effects of medication could wear off. If toilet facilities were out of order, disabled people could face highly embarrassing and traumatic situations. If live journey information was unavailable, disabled people could miss their stops and be left stranded. All kinds of unplanned changes to journeys could cause high levels of anxiety and psychological distress for disabled people, for those with mental health conditions and those without.

Feelings of autonomy, confidence and deservingness

For some disabled people, decisions about whether and how to travel were based on whether they would be able to do so without assistance and with a feeling of personal control. This often meant avoiding public transport in favour of private transport: driving, or being driven by a trusted companion. This enabled disabled people control over their physical exertion and their immediate environment, and allowed them to return home at any time. By contrast, journeys on public transport could involve a feeling of being at the mercy of factors that were beyond one's personal control.

Some disabled people did feel a sense of autonomy and independence on public transport, and this was often related to their feelings of confidence and their perceptions of their own disability. Some disabled people were highly confident about making their needs known to staff and other passengers, such as asking for assistance, asking for a priority seat, or using accessible toilets. But others were much less confident and could feel embarrassment or shame, or could feel they did not deserve assistance because they were not 'disabled enough'. These disabled people often had less visible disabilities and were anxious about societal preconceptions of what disability looks like.

The uniqueness of individual needs and preferences

Throughout the research, it was clear that needs and preferences of disabled people were highly varied and often unique to each individual. The precise combination of health needs, travel needs, and personal resources meant that no two disabled people had the same set of preferences for public transport.

A crucial dimension of variation was the extent of personal and financial resources available to disabled people, which determined the range of transport options open to them. Some disabled people had access to a car whereas others did not. Some had higher incomes than others, meaning that they could take more expensive modes of transport, such as taxis, which better met their needs. Those on very low incomes, who in some cases were struggling to find work that was compatible with their health condition or impairment, could be left isolated and unable to afford any transport options that met their needs.

There were many other dimensions of variation, which are discussed throughout this report. There was variation in the extent to which disabled people prioritised space on vehicles – wheelchair areas and the width of aisles – or prioritised seating. Some disabled people found buying tickets from machines challenging or stressful, and preferred buying from staff, whereas others found interacting with staff difficult and anxiety inducing, and preferred machines. There was wide variation in preferences for onboard audio-visual information, with different groups preferring audio announcements, visual announcements, apps and websites, or simply getting information from staff.

Improving the transport network for all

Despite this diversity in needs, there were nonetheless some factors that were universal. While these tended to be factors that were also important to non-disabled people, it was clear from the research that improvements that would benefit all transport users would disproportionately benefit disabled users. Most obviously, given the need for high levels of certainty, disabled people would disproportionately benefit from improved reliability and regularity of services.

But perhaps the most consistent and important factor that recurred throughout the research was the challenges posed by overcrowding. When stations and vehicles were particularly busy, this had a wide range of profound impacts on disabled people:

- Difficulty reaching or accessing seating, which was needed to avoid pain or fatigue
- An increased likelihood of bumps and falls for those with impaired strength or balance
- Difficulty seeing or hearing live journey information
- Severe social anxiety associated with being in close proximity to other people
- Difficulty reaching wheelchair spaces
- Risk of injury for assistance dogs
- Difficulty accessing staff for information or assistance

These factors meant that disabled people tended to actively avoid travelling in busy periods. If travel was unavoidable – for example, travelling to or from work – then it was common for disabled people to use alternative, and more expensive, modes such as taxis. Efforts to reduce overcrowding would therefore have a disproportionate benefit for disabled people.

1.2 The structure of this report

This report is structured according to the following chapters:

1. **Executive summary.** The first chapter provides an overview of the key findings.
2. **Introduction & research methodology.** The second chapter provides background to the ITS and research, including a summary of data collection methods.
3. **Travel experiences.** The third chapter explores disabled people's lived experiences of the transport system (positive and negative), and their suggested improvements to it. It is structured according to the stages of a typical journey by public transport.
4. **Decision making.** The fourth chapter explores how disabled people make decisions about whether and how to travel. It is structured according to seven key factors that crucially underpinned disabled people's decision making.
5. **Discussion**. The fifth and final chapter considers what the findings mean for the future of inclusive transport.

2 Introduction & research methodology

2.1 Background

Despite the essential role that transport plays in everyone's lives, disabled people are disproportionately affected by barriers to travel. The Department for Transport's (DfT) Inclusive Transport Strategy seeks to remove these barriers so that, by 2030, disabled people have equal access to the UK transport system, with assistance where physical infrastructure remains a barrier. The ITS vision is underpinned by three core aims – for disabled people to travel **confidently**, **easily** and **without extra cost**.

2.2 Evaluation of the ITS

The DfT seek to monitor the progress of ITS, in order to:

- Learn and build an understanding of the actions that represent best value for money and use the findings to develop further policy interventions
- Understand how the landscape of inclusive transport is changing to help to inform where future efforts should be directed
- Make the results of the ITS visible to stakeholders, including disabled people and Parliament

The DfT commissioned the National Centre for Social Research (NatCen) to conduct an evaluation of the ITS on their behalf. NatCen's evaluation involves two waves of mixed-methods research. The first wave was conducted in 2020 and its finding are available in a baseline report. The second wave will be conducted in 2023.

This report focusses exclusively on analysis of qualitative interviews undertaken with disabled participants during the first wave of data collection. While findings from these interviews were also covered in the baseline report, it was structured according to different modes of public transport and policy driven themes laid out by the ITS paper published in 2018 (improved information and awareness; inclusive infrastructure; better staff training; and promotion of passenger rights and enforcement). By contrast, this report provides a richer picture of the lived experience of disabled people and how they consider and use the transport network as a whole. It aims to capture the nuance and complexity and individuals' circumstances and experiences, and to give greater voice to disabled people themselves by the use of 'pen portraits' throughout.

2.3 Research aims

This report and analysis set out to understand the following:

1. What journeys disabled people take, and their positive and negative experiences on those journeys.
2. How disabled people feel the transport network could be improved for them.
3. How disabled people make decisions about whether and how to travel.
4. How disabled people's views, experiences, and decision making can be grouped by attitudes, behaviours, circumstances or shared characteristics.

2.4 Defining and analysing ‘disability’

For the purposes of this research, we defined disability in line with the Equality Act 2010. This definition considers a person disabled if they have a physical or mental health condition or impairment, lasting or expected to last 12 months or more, which has an impact on their ability to carry out day-to-day activities.

2.5 Interviews with disabled people

The first wave of the ITS evaluation involved extensive primary research, including a nationally representative survey of disabled people and the travelling public, and follow-up qualitative interviews with disabled people. These qualitative interviews took place between August and September 2020. Participants were recruited through the survey, using a purposive sampling approach to achieve range and diversity across key characteristics such as disability or impairment, type of travel, and age.

The interviews supplemented the survey by providing an in-depth view of disabled peoples travelling experiences and the key facilitators and barriers to travel. Participants were asked about how their disability or impairment impacted their travel behaviours; their most common journeys; the barriers they faced to making other journeys; and their suggestions for improvements. The interviews commenced at a time when the COVID-19 pandemic was significantly impacting the extent and nature of transport use. For this reason, we asked participants to reflect on their experiences prior to March 2020. The Technical appendix in this report provides a detailed methodological overview of our interviews with disabled people and a full technical report covering all of our primary baseline research was published alongside the baseline report. Both can be accessed via GOV.UK.

2.6 Analytical approach

Interviews were transcribed then thematically categorised using Framework in NVivo, a qualitative data management approach developed by NatCen (Ritchie et al., 2013). A matrix was set up, with each column representing a key sub-theme and each row representing an individual case. For each case, data relating to each sub-theme was summarised within the relevant cell.

The categorisation of data produced for the ITS baseline report was structured around transport mode, key barriers and enablers and suggested improvements. As this didn’t fully cover the scope of additional analysis, the matrix was expanded to capture information about disabled people’s decision-making processes.

This supplementary analysis involved recategorising the data according to the revised matrix, before seeking to identify similarities, differences and thematic patterns. Throughout this process, we explored whether disabled people’s choices and experiences could be classified according to characteristics such as disability type, demographics or by overall attitudes. Given that the study adopted a purposive sampling approach (see 2.7), the findings presented in this report should be read as mapping out the range and diversity of disabled people’s lived experiences, rather than a statistical representation of the disabled population at large.

2.7 Use of pen portraits and quotations

Throughout the report, we use pen portraits and quotations to illustrate the range, complexity and nuance of disabled people’s lived experiences. Each example is labelled with key characteristics such as age, gender and disability type. To protect the anonymity of participants, further information has either not been stated or certain details including names have been changed. Where participant details have been changed, we ensured to do so whilst staying true to what they told us about their experiences of the transport system.

2.8 About the participants

Key characteristics and transport use

Care was taken to ensure that participants had a wide range of different personal circumstances and needs, including:

- Age (18-39; 40-64; 65+)
- UK region (England; Scotland; Wales)
- Geography (urban or rural)
- Public transport use (users and non-users)
- Number of transport modes used (single or multiple)
- Type of transport modes used (personal car; Taxi/PHV; bus; train; plane; boat/ferry)
- Employment (employed; unemployed; retired; commuters and non-commuters)

Disability type

Throughout the report, we refer to the following categories of health condition or impairment. Though the experiences of each group were generally distinct, they could interact in complex ways for those with multiple health conditions or impairments, who were widespread across the sample. For each category, we provide examples of the health conditions included. These examples are *indicative*, and not an exhaustive representation of every health condition in the sample.

Physical health conditions that limit mobility stamina or dexterity. This category refers to health conditions that caused symptoms such as pain, fatigue, breathing difficulties or other types of physical discomfort as a result of standing, walking or general physical exertion. Participants ranged from travelling unassisted, to always using some form of mobility aid or other physical assistance during travel.

Examples: arthritis (rheumatoid arthritis and osteoarthritis), asthma, chronic obstructive pulmonary disease (COPD), Ehlers-Danlos Syndrome, diabetes, dyspraxia, functional neurological disorder, heart-related diseases, multiple sclerosis, peripheral neuropathy, post-polio, prolapsed disc, sciatica, slipped epiphysis and spinal stenosis.

Physical health conditions that limit digestive, bowel or bladder function. This category refers to digestive, bowel or bladder conditions that limited the ability to carry out day-to-day activities, typically due to an urgent need to use the toilet, incontinence and difficulty maintaining energy or regulating temperature specifically as a result of a digestive health condition (for example, poor digestive function as a result of cancer, enlarged prostate, overactive bladder and ulcerative colitis). Some, but not all, in this category were users of Changing Places toilets. The category also includes those with an ileostomy/stoma.

Other physical health conditions. The experiences of those with certain health conditions were distinct, meaning that they had less in common with the experiences of those with other types of health condition. This included participants with epilepsy, or a speech impairment. Where this is the case, we refer to the single health condition, rather than referring to a group of health conditions.

Mental health conditions. This category refers to health conditions that primarily impacted emotional, psychological or social wellbeing. Such conditions typically limited the ability to carry out day-to-day activities without experiencing adverse reactions in response to triggers.

Examples: anxiety (and social anxiety), depression, obsessive compulsive disorder (OCD), post-traumatic stress disorder (PTSD) and schizophrenia.

Cognitive impairments. This category refers to impairments that caused difficulties with learning, understanding or concentrating; problems with memory; or social or behavioural difficulties. Cognitive impairments were caused by a variety of factors (for example, medication) and health conditions (for example dyspraxia).

Visual impairments. This category refers to sight loss that reduced the ability to carry out day-to-day activities. The sample included those who travelled with and without travel aids (including assistance dogs).

Examples: blindness and general vision loss, or visual impairments that were caused other health conditions such as diabetes.

Hearing impairments. This category refers to hearing loss that reduced the ability to carry out day-to-day activities.

Examples: general hearing loss, or hearing impairments that were linked to other health conditions such as dyspraxia.

3 Travel experiences

This chapter provides insight into disabled people's lived experiences of the transport system and their suggested improvements to it. While many of the themes discussed here are also discussed in the ITS Evaluation Baseline Report, this chapter provides richer detail, bringing out the variation between disabled people's experiences and the complexity of individual circumstances. In the next chapter, we provide more detail about how these positive and negative experiences informed current travel decisions.

This chapter is structured around the typical stages of a journey, as follows:

1. **Journey planning.** Experiences of planning in advance of a journey.
2. **Making the journey.** Experiences of *getting to* transport/interchange hubs and then using them.
3. **Accessibility and comfort.** Experiences when boarding and alighting transport, and when onboard.
4. **Passengers and staff.** Experiences of passengers and staff (throughout the entire journey).

Suggested improvements to the transport network are only included where participants put them forward. As not every theme received recommendations during the interviews, not every section of this chapter presents suggested improvements. It is also worth noting that different disabled participants expressed different needs and recommendations, which were sometimes incompatible without wider changes to the transport network. For example, it is not necessarily possible to provide wider aisles on trains *and* provide more seating, but increasing the frequency of trains could help resolve this tension.

3.1 Journey planning

Planning in advance was often a crucial factor in positive travelling experiences. Journey planning involved using apps or websites, calling information desks or accessing information at stations. Participants used journey planning to become informed about their journeys and therefore to be more confident travelling. Planning was important across transport modes but especially for longer journeys and those involving changeovers or multiple modes of transport. Below, we explore three ways in which journey planning underpinned positive travelling experiences.

Minimising delays and uncertainty. Planning enabled participants to tailor aspects of their journey such as mode and route to their health-related needs. For example, it enabled car users to opt for routes without delays, familiarise themselves with the route in advance and facilitated parking in close proximity to their destination; it also enabled public transport users to be informed about journey delays and find alternative routes, as well as ensuring that the routes they take have the necessary facilities, such as toilets. The inability to plan journeys could have severe consequences for disabled people. For example, significant pain and fatigue during prolonged waits for transport, heightened anxiety, increased risk of incidents such as a seizure or the inability to find toilet facilities in time.

Reducing social anxiety. For those with mental health conditions or cognitive impairments, journey planning could negate the need for interaction with transport staff. Staff interaction often created stress and anxiety for both groups, for different reasons. Participants with cognitive impairments could find it difficult to understand others or make themselves understood, whilst for those with mental health conditions, any social interaction could be anxiety-inducing. Planning in advance enabled participants to minimise staff interaction in the following ways:

- *Buying tickets online*, to avoid having to queue amongst other passengers or speak to staff at a ticket desk.
- *Taxi-booking apps* were used to hail taxis and give the driver instructions without the need for verbal communication.
- *Scheduling journeys outside of rush hour*, to avoid crowds. This was not only important for those who experienced social anxiety, but also those who experienced anxiety in relation to other health risks associated with crowds, for example, heightened risk of being in physical pain.

Confirming that a journey would be physically accessible. For those with a physical health condition that limited mobility, stamina or dexterity, planning was important for checking train station accessibility. For example, disabled people checked the availability of lifts and whether stations were undergoing work that would make it difficult to get to the platform. Buying tickets online was also important across modes, as it removed the possibility of experiencing physical discomfort when queuing. It also allowed participants to book assistance or specify accessibility requirements such as seats with extra legroom, to ease physical discomfort.

3.2 Making the journey

This section outlines the factors that contributed to disabled people's ease of travel when getting to transport and interchange hubs, and when using them. These included the positioning of transport and interchange hubs (i.e. accessibility in the location and vicinity of hubs); the provision and signposting of physical transport infrastructure at transport hubs; and the provision of key services including ticketing, concessionary travel schemes and live journey information.

The positioning of transport and interchange hubs

Disabled people's travel experiences were underpinned by the safe and accessible provision of transport and interchange hubs. The location of hubs could be a barrier. Those with physical health conditions that limited mobility, stamina or dexterity and those with visual impairments emphasised the importance of transport hubs being located on level ground. Less accessible locations, such as the top or bottom of a hill, could create or exacerbate physical discomfort.

The infrastructure in the local area around hubs could also create barriers. Participants highlighted the following factors as important for ensuring accessibility:

- *Pedestrian crossings*. Placing pedestrian crossings near transport hubs was important for those who would struggle to quickly cross a busy road or walk a long way to get to a crossing.
- *Streetlights*. Providing lighting around transport hubs was vital in enabling people to better see their surroundings, including potential obstacles, and to safely get to and from their mode of transport.
- *Removing obstacles*. Obstacles in the vicinity of transport hubs (for example, outdoor café seating and cars or e-scooters parked on nearby pavements) could lead to bumps and falls. They could also push travellers to use a different route or enter the road.
- *Dropped curbs*. Dropped curbs were essential for participants with mobility aids, such as wheelchairs and walking frames, to be able to get on and off pavements and to get around obstacles safely.
- *Even pavements*. Poor maintenance of the pavements surrounding transport hubs could lead to serious trip hazards.

The provision and signposting of physical transport infrastructure

The following features of physical transport infrastructure were important when navigating or waiting at transport hubs.

The consistency and accessibility of lift provision. Where train stations lacked lifts, this meant participants had to undergo significant physical exertion and journey disruption in order to access the platform. For example, a participant stated that in the absence of a lift they either had to use the underpass or go to another station entrance with fewer steps, both of which were physically demanding for them. Furthermore, where lifts were provided, they were not always located in plain sight or adequately signposted. This made it difficult to get to a lift, or to even know it was there. These difficulties were compounded for people with multiple conditions, such as a cognitive impairment and physical health condition, as it made both walking and following directions when looking for a lift difficult. Finally, participants said that some lifts were too small to fit into with a mobility aid. They also criticised the provision of escalators in place of lifts, as they were difficult or impossible to use while holding onto aids such as crutches or walking frames.

The provision of shelter and seating. Having to wait at transport hubs with inadequate shelter could have severe consequences for disabled people. For example: for those with lung conditions, waiting in areas that were old or smelt, bad negatively impacted breathing; for those with arthritis, waiting in low temperatures increased sensitivity to joint pain; for those with limited digestive, bowel or bladder function, waiting in cold weather could be very uncomfortable due to difficulty regulating body temperature; and for assistance dog users, waiting without shelter created extra work when their dog became wet. Similarly, inadequate seating at stations and stops was a barrier to travel for participants who experienced physical discomfort when standing or moving. A participant with a physical health condition carried a portable chair with them to avoid discomfort when waiting at their local bus stop. Finally, for participants with anxiety, having somewhere quiet to sit down helped reduce stress prior to a journey.

Improvements

Suggested improvements to the waiting experience included:

- Providing more seating at transport hubs
- The provision of live bus arrival times at bus stops so that disabled passengers can estimate when transport is due and how long they must wait
- Providing quiet areas so that those experiencing anxiety can wait in a calm environment

Pen Portrait: the importance of physical infrastructure for those with mobility impairments

Shona is in her fifties and lives in a city. She regularly uses taxis, and occasionally trains and buses. She often uses mobility aids to help her get around.

Shona's biggest barrier to travel is the physical inaccessibility of public transport. On the way to her local train and bus stations, the surrounding pavements often lack drop-kerbs, which is particularly challenging when using her walking frame. Sometimes she must go in the opposite direction of the station to cross the road. Outdoor cafes in the proximity also limit pavement space:

"When you have these cafes with table and chairs outside, it limits the pavement. Then you have to wait in a queue to pass, or there isn't enough room and your walking frame falls off the end of it. That's quite difficult."

Shona must use the footbridge to change platforms at stations without a lift, which is painful and very difficult with her walking frame. At her local bus stop, Shona struggles with the lack of seating due to the pain she feels when standing. She also struggles to board and alight transport. However, she finds the bus driver typically does not wait at the bus stop long enough for her to get up and alight the bus before moving again, which forces her to stand up and move down the bus ahead of the stop, while the bus is still moving, despite the pain and risk of injury this involves.

Due to these challenges, Shona struggles with any journey by public transport, especially multi-mode journeys. She therefore prefers to use taxis, which are more physically accessible to her, and so she experiences less anxiety in comparison.

Providing a range of ticketing modes

The availability of preferred modes of purchasing tickets was an important factor in positive travel experiences. Some disabled people preferred modes that enabled them to avoid interacting with staff, whereas others had an active preference for staff assistance.

A preference for ticket machines or contactless payment systems. Those who generally avoided social contact were more confident when using ticket machines or contactless payment systems, as it meant they would not have to speak to anyone. For example, this was important for those who struggled to communicate with staff as a result of their anxiety or a hearing impairment. However, these ticketing modes could not always be relied on, for example because not all transport hubs had contactless payment systems, or because ticket machines were not always working. The former was commonplace in rural areas. These barriers forced participants to stand in queues or interact with staff to buy tickets, which could trigger physical discomfort or anxiety.

A preference for staff assistance. Other participants preferred buying tickets with staff assistance. Ticket machines could be confusing and awkward to use, particularly for those who needed to apply concessionary discounts. Participants with cognitive difficulties also struggled to work the machines in a short space of time, and some said they felt self-conscious as they felt they were holding up the queue when figuring out the machine.

However, there were a range of challenges experienced when purchasing tickets from staff. At ticket desks and on buses, participants with hearing or cognitive impairments struggled to hear and understand staff due to the thick glass and poor-quality microphones. Bus drivers also tend to face forwards when answering questions, which made it difficult for those who relied on lip-reading. Furthermore, some participants said ticket staff and bus drivers had showed impatience when dealing with their questions and when asked to repeat themselves. This could trigger anxiety when participants were unsure they had correctly heard or understood information, for example if they wanted to check that they had the right ticket or were taking the best route. This often led them to give up on speaking with staff altogether.

Improvements

Suggested improvements to ticketing included:

- Providing priority boarding to speed up the process of boarding a bus for disabled passengers who are less able to stand when queuing, particularly for buses that lack contactless payment systems (e.g. in rural areas).
- Providing a system whereby passengers with mental health or physical conditions can board first.
- Providing more options for pre-booking tickets across transport modes e.g. being able to buy bus tickets online and in shops.

Pen Portrait: the importance of journey planning and pre-purchasing tickets for reducing anxiety

Tom is in his twenties and lives in a town. He suffers from anxiety and depression. He uses the bus on a weekly basis, the train monthly and taxis occasionally.

Tom's biggest obstacles when travelling include the 'unknown' and social interaction, both of which cause him a great deal of anxiety. He therefore plans travel in advance so that he knows how his journey is going to go and pre-buys tickets when possible to avoid interaction with other passengers or transport staff when queuing.

When he cannot pre-buy tickets, Tom prefers to use contactless cards. However, this service isn't available everywhere in his area. Live bus journey information is also not provided, meaning that he is less aware of upcoming delays or route changes, which decreases his confidence to travel. It also means that he often must wait for a long time at bus stops among other people, which heightens his anxiety.

"The main thing that is a problem with large-scale public transport, I guess, is just the number of people that are there… I always try and buy my tickets online beforehand and all that kind of stuff so I have the minimum amount of interaction needed when I'm there."

Onboard transport, Tom likes to sit or stand away from people whenever possible and so travels early to avoid crowds. He values audio-visual announcements as on busy days it's difficult to see through transport windows, and announcements negate having to ask staff or passengers about the journey, especially in unfamiliar places.

The adequacy of concessionary travel schemes

Concessionary travel schemes enabled participants to take longer, more complex or more accessible journeys. However, such benefits could be compromised by the following barriers.

Low awareness of concessionary travel schemes. Not all participants were aware of concessionary travel schemes, or how they worked. Some suggested the schemes did not apply to them when it was likely to. This was particularly true of participants with mental health conditions and those with non-visible physical health conditions.

Restrictive time limits. Participants argued that having concessionary travel windows starting at 09:30 was unfair for those with early morning commitments. Furthermore, they said car journeys were hindered by the three-hour time limit on blue badge parking. This particularly impacted participants with mobility impairments who struggled to get to and from their destination before the three hour window expired.

Low availability of blue badge spaces. Participants said that finding disabled parking spaces could be difficult, particularly at peak times or in locations where demand was higher, such as in hospitals. Those with physical health conditions that limited mobility, dexterity or stamina, would physically struggle if parking close to their destination was not always guaranteed. This was particularly true for mobility aid users, who required the additional space provided in disabled parking bays when entering or exiting their vehicle. Some participants described giving up and returning home if they could not find a disabled parking space.

Improvements

Suggested improvements to concessionary travel schemes included:

- Relaxed time restrictions on concessionary travel, so that disabled people can benefit from free travel during peak hours.
- Relaxed time limits for blue badge parking, to provide people with mobility-related conditions enough time to get to and from their destination.

The provision of live journey information

Disabled passengers relied heavily on live journey information and were severely impacted when its availability or accessibility was inadequate. Live journey information includes audible and visible announcements at stations or onboard transport and online travel information. Having access to multiple forms of live journey information underpinned participants’ ability to travel with confidence and without stress. For example, those with hearing and visual impairments relied heavily on such information to know where they were or what their next stop was. Meanwhile, it acted as a vital source of reassurance for those with anxiety, as it provided a way to easily check the status of their journey or to find alternative transport without experiencing uncomfortable social interactions. Participants cited two main difficulties accessing live journey information.

Inconsistent provision of audio, visual and online information. Participants stated that many modes of transport, particularly in rural areas, still do not provide visual or audio journey information at transport hubs or onboard transport, or that provision is inconsistent. Participants with hearing or visual impairments shared that a lack of visual and audio information at transport hubs makes it challenging for them to catch connecting transport on multi-mode journeys. Participants also stressed that mobile phone signals don’t always work onboard transport, especially in remote areas, and that Wi-Fi is rarely provided. As a result, live online travel information was not always available.

Inconsistent provision of information in accessible formats. For those with visual impairments, digital or printed information boards were often too small to read or used less visible colours. Furthermore, those with cognitive impairments struggled to follow scrolling LED displays, as they could not read the information fast enough or it was not displayed long enough to be remembered. Automated audio announcements and tannoys could also be difficult to hear and understand due to background noise or poor-quality audio, especially for those with hearing impairments. Furthermore, consuming online information could be challenging for participants with visual impairments, as not all travel apps and websites displayed text and digital layouts in a large enough size for those with visual impairments to read, even if they used larger screen phones to assist with their visual impairment. Additionally, for participants with cognitive impairments, information such as station maps, journey instructions and directions were not always provided in a way that was easy for them to understand and follow.

Improvements

Suggested improvements to the provision of audio-visual information included:

- The universal roll-out of automated audio announcements onboard transport and at transport hubs.
- Providing more live information screens onboard transport and at transport hubs.
- To improve ease of understanding for those with cognitive impairments, screens should display previous and upcoming stops; estimated arrival times; a visual representation of where on the route the passenger is (for example having dots for each station that light for the current stop).

- Providing a greater variety of written and visual information to meet the needs of people with different conditions.

3.3 Accessibility and comfort

This section explores the factors that contributed to disabled people’s experiences of accessibility and comfort on journeys. It starts by considering the physical accessibility of vehicles themselves, before discussing the importance of adequate provision of toilets.

The provision of accessible and comfortable vehicles

Once onboard transport, experiences were affected by the level of accessibility and comfort the vehicle provided. This included having aisle access, having suitable seating and having control of their access to fresh air; control of the temperature; or of the level of noise they were subject to.

Having aisle access. Having easy access in and out of aisles was important for a range of groups, as it facilitated further ease of access to seating, toilet facilities and standing space. Participants faced three barriers to having easy aisle access:

- *Insufficient space*. A lack of space onboard was a barrier for users of mobility aids, (such as walking frames, wheelchairs and motorised scooters) as they struggled to fit onboard transport or down aisles. Meanwhile, for those with mental health conditions, a lack of space decreased travelling confidence as it meant having to be too close to other passengers, which could be triggering.
- *Lack of level flooring*. Uneven flooring, such as the step at the back of a bus, made it difficult for participants with physical health conditions that limited mobility, stamina or dexterity and those with visual impairments to use aisles. Participants explained that it helps when train coaches are connected as they can easily walk from one end of the train to the other should they need to.
- *Lack of handrails onboard transport*. Handrails were important for participants to keep stable, both when walking down aisles and sitting. However, participants noted a lack of rails onboard, for example in pushchair areas. A participant felt there was a lack of rails onboard newer trains, particularly in the spaces between carriages. For those less able to stand, this increased the risk of losing balance and incurring pain, injury or other physical discomfort.

Access to suitable seating. Those with physical health conditions that limited mobility, stamina or dexterity emphasised the need for wider seats with more legroom, to ease physical discomfort and minimise the chance of injury. When travelling by taxi, participants expressed varying preferences for the size or height of the vehicle and seating. For example, while low floor taxis could be easier for those with physical health conditions to get into, a participant with arthritis preferred higher vehicles as getting in and out of them placed less pressure on their knees than low floor vehicles, which helped to limit the pain they experienced. This was also important for a participant with epilepsy, for whom bumps or injuries could trigger a seizure. Furthermore, for those with mental health conditions, single seating and seating facing forwards was often preferable as being close to others or facing backwards could trigger anxiety.

Fresh air, temperature and noise. Other aspects of the travelling environment were important for travelling in comfort and without pain or stress when onboard public transport. For those with breathing conditions and those with epilepsy, the ability to open windows was important as stale air contributed to breathing difficulties and overheating could lead to seizures. Meanwhile, strong air conditioning caused instant and severe facial pain for a participant, which meant that ability to control air conditioning was important for some. Finally, having catering and quiet space onboard trains, especially on long journeys, helped participants with mental health conditions to feel calmer when travelling.

Improvements

Suggested improvements to the accessibility and comfort of vehicles included:

- More space onboard public transport, including wider aisles on trains. However, other participants wanted more seating, including single seating and more space around and in between seats.
- Dedicated spaces for disabled people on all public transport modes
- The ability for passengers to specify the kind of taxi or PHV that would suit them best (e.g. the ability to request taxis of different heights or sizes)
- Ensuring windows can be opened, and are easily accessible by all

3.4 Passengers and staff

This section looks at participants experiences with passengers and staff throughout their journey. It will explore experiences of crowding, accessing seating or priority spaces, toilet facilities and staff assistance/assistance schemes.

Difficulties that arise from crowding

Crowding was cited as one of the biggest barriers to travel across modes. Disabled people often avoided travelling during peak hours due to crowding, while those who travelled at rush hour experienced the following challenges:

- *Difficulty manoeuvring around passengers* when boarding or alighting public transport, especially for those who travelled with a mobility aid or assistance dog.
- *Difficulty hearing announcements*, due to the noise generated by crowding. This was cited both by those with and without hearing impairments.
- *Heightened anxiety* in close proximity to other passengers. This was cited both by those with and without mental health conditions.
- *Difficulty accessing staff assistance*, due to low staff presence during rush hour. Staff were also deemed to be less helpful at this time, as they were busy.

Improvements

Suggested improvements to mitigate crowding on public transport included:

- Greater provision of seating
- Increasing staff presence, so that disabled passengers can receive help in asking non-disabled passengers to vacate seating and priority spaces if needed
- Providing announcements that inform non-disabled passengers to vacate their seats for disabled passengers.
- Lowering taxi fares for disabled people during peak hours, to meet the needs of those who cannot travel by public transport when it is crowded but also struggle to afford the additional cost incurred when travelling by taxi

Difficulties accessing seating or priority spaces (at any time)

Participants outlined further ways in which other passengers increased the difficulty of travel on public transport, regardless of how busy it was. Difficulties included an unwillingness or slowness to vacate seating, priority seating and other priority spaces (including wheelchair spaces, accessible toilets and the front of the queue).

For example, participants consistently told us about experiences where pushchair users had occupied priority seating and wheelchair spaces, and other passengers had failed to vacate priority seating. This had, in some instances, led participants to sit in standard seating for one of three reasons: firstly, because other passengers had refused to vacate priority spaces and seating; secondly, because participants did not feel confident in asking another passenger to move in the first place; or thirdly, because they worried that other passengers may need the seat more than them (for example, if they had a non-visible disability). Standard seating was often less comfortable and further away from the exit, which typically increased difficulty of boarding and alighting for those with physical health conditions that limited mobility, stamina or dexterity and those with visual impairments.

This issue stood out most among those with non-visible health conditions. The experiences of this group are covered in fuller detail in Section 4.6.

Improvements

Suggestions to improve access to seating/priority spaces included:

- Promoting greater awareness of journey assistance tools (such as the Hidden Disabilities lanyard) to those with non-visible health conditions, as well as greater understanding of their benefits and how to apply for and use them
- Promoting greater awareness and understanding of non-visible health conditions for example by displaying signs that inform passengers to be aware of passengers with non-visible conditions and inform them on what to look out for

Pen Portrait: the difficulty of accessing seating for those with a non-visible disability

Sara is in her thirties and has epilepsy. She lives in a town and typically uses buses or trains to travel. Sara’s greatest needs when travelling are avoiding situations that could trigger a seizure, and managing the anxiety induced by the possibility of experiencing one when out.

Onboard transport, Sara places herself near windows as overheating can trigger a seizure. As most train windows cannot be opened, she often relies on air conditioning, which is not always adequate. It is also important for Sara to be seated, as bumps and falls can trigger a seizure. However, in the presence of older people, she usually vacates her seat for fear of judgement from other passengers who cannot see why she needs it.

“The worst part is just the fact that it's an invisible thing and that people aren't aware.”

Sara also worries that if she did experience a seizure, it would not be obvious to others that she required help until it was already happening, especially on a crowded journey. For this reason, she feels that getting a Hidden Disabilities lanyard could improve her experience of public transport. Finally, access to toilet facilities and refreshments on longer journeys is also essential to managing her anxiety.

The adequate provision of toilet facilities

Having easy access to toilets, including standard and accessible facilities, was a vital part of travel, particularly for those with physical health conditions (including those that had limited mobility, dexterity or stamina and those with limited digestive, bowel or bladder function) and those with visual impairments. However, interviews revealed three shortcomings in toilet provision, as outlined below.

A lack of toilets. Participants highlighted the inadequate provision of toilet facilities onboard coaches, on certain train routes and at smaller train stations. Difficulties included provision of facilities that were inconveniently located, required staff keys to access or which were pay-to-use and required exact change. These were all barriers that could not always be overcome quickly enough when participants' health condition meant they needed use of toilet facilities urgently.

A lack of space and washing facilities. Mobility aid users had experienced difficulties with the limited size of toilet facilities onboard public transport, at transport hubs and at motorways. Such facilities often did not fit wheelchairs or walking frames, making them very difficult to use. Spacious toilets were also necessary for participants with physical health conditions that limited digestive, bowel or bladder function, who typically required the additional space for changing and putting belongings down. Additionally, accessible toilets typically lacked full washing facilities, which was particularly problematic for those with limited bowel function. It's worth noting that not every participant who spoke about the limitations of accessible toilets cited a need to use the additional facilities provided in a Changing Places toilet.

> *"I've got nowhere to put anything. You can even end up putting things on the floor because there's nowhere [else]. There are so many things I need to do and there aren't of course the washing facilities. You might get a bit of dribble out of the tap but nothing that would help me very much. It's mainly a very stressful experience." [Female, 65+, physical health condition]*

Inadequate 'accessible' toilets. Participants said that not all accessible toilet facilities are designed to be practical for *all* disabled people. For example, they typically prioritise wheelchair users, with features such as basins placed lower down. Such arrangements caused difficulties for non-wheelchair users with limited mobility and dexterity.

Improvements

Suggested improvements to the provision of toilet facilities included:

- Increased provision of accessible toilets
- Providing full washing facilities and adequate space in all accessible toilets

The provision of general staff assistance

Participants had experienced both positive and negative experiences with staff. While some found staff to be helpful, others had experienced a low staff presence on public transport, a lack of assistance to overcome vehicle inaccessibility and a lack of support or lack of disability awareness from staff.

A low staff presence and lack of support. Participants often argued that more staff were needed at stations, platforms and onboard transport, to provide support such as telling non-disabled passengers to vacate disabled spaces. It was also argued that staff need to show greater readiness to support disabled people should they suddenly feel unwell or require help unexpectedly.

> *"At train stations I just don't think that there's an awareness or there's a want to help because they're so busy. There's just not enough people and if there is enough people, they're just not interested." [Female, 40-64, physical health condition]*

Providing assistance to overcome vehicle inaccessibility. Transport staff often played an important role in bridging the gaps in the accessibility of physical infrastructure. For example, those travelling with a mobility aid (such as a walking frame or crutches), shopping or luggage often required physical assistance from staff to climb steps, as they could not simultaneously hold onto what they were carrying and the handrails. This was particularly an issue on buses, but also larger taxis. Though designed to provide more space for users of mobility aids, larger taxis could be difficult for participants to climb into, thus requiring physical assistance from the driver. However, staff were not always forthcoming in offering such assistance. For example, it was highlighted that drivers only tend to lower the bus or bring out the ramp for passengers with visible mobility aids, such as wheelchairs, leaving those with non-visible physical health conditions without assistance. Furthermore, participants said that, once onboard, bus drivers often do not wait for passengers to sit before driving off, which can cause a loss of balance, pain or injury for those less able to stand.

> *"I would want the driver to stop at the stop and not expect me to be walking down beforehand […] I fell flat on my face and I broke three teeth, and I was really, really upset. The bus driver really, really didn't give a toss and it was other passengers that picked me up." [Female, 40-64, physical health condition]*

Likewise, some participants said that when getting off buses or trains, they did not always have enough time to get from their seats to the door, as they were unable to stand up while the vehicle was moving.

> *"I always have to wait for the train to stop before standing up. If you're a bit further back, it obviously takes you a bit longer […] you feel like you've barely got enough time to make it off." [Female, 40-64, physical health condition]*

A lack of disability awareness. Participants explained that staff do not always provide them with the correct support for their needs. For example, someone with a visual impairment said that staff would sometimes give them a wheelchair to sit on even though they did not have a physical health condition, which they found to be confusing and humiliating. Participants expressed that, if staff had greater disability awareness, they could more easily tailor the assistance they offer to what disabled passengers need. They also emphasised a particular need for greater awareness of non-visible health conditions, as the needs of those affected are not obvious, meaning they are less likely to be offered assistance at all.

Improvements

Suggested improvements to staff assistance included:

- A greater staff presence on transport and at transport hubs, for example to help disabled passengers who feel unwell or can't access seating/priority spaces
- Ensuring that all passengers have enough time to board the bus and sit down before it drives off – whether they are visibly disabled or not
- Ensuring that staff always show patience and understanding when communicating with disabled passengers
- Greater disability awareness training for staff and drivers, so that they can correctly identify when people require assistance and know how to offer the correct support

Pen portrait: the importance of staff assistance for those with cognitive impairments

Claire is in her fifties and lives in a city. In a typical week, she regularly uses her local bus and underground system. She has a combination of cognitive, hearing and speech impairments, as well as physical and mental health conditions.

Due to her cognitive impairment, Claire struggles to receive information in the form of maps, signs and directions. Advance planning is therefore very important as she can choose more convenient routes that limit any confusion or uncertainty. Onboard transport, Claire struggles to read scrolling LED displays or hear audio announcements and finds using the internet on her phone 'too fiddly'.

Claire's greatest travelling need is being able to receive information and reassurance from staff, so that she can be confident in where she is going. However, Claire's hearing and speech impairments make it difficult to communicate and she says that staff typically become impatient with her as they do not understand her needs.

"I really don't feel that [transport staff] like to see me coming twice, and I am one of those people which appear to be a pest to those who don't know my disabilities. I like to understand and to re-check and check again and I seem to get on their nerves."

The provision of assistance schemes

Disabled people with a wide range of different health conditions and impairments had used assistance schemes, particularly those with vision impairments and physical health conditions that limited mobility, dexterity or stamina. They expressed that such schemes helped them to access transport and complete changeovers. Participants had used assistance schemes on trains or planes, and some suggested the service be extended to other modes such as buses. However, two key deficiencies in assistance scheme services were noted.

Failed assistance. Not all users of booked assistance felt that it could be relied on. For example, a visually impaired participant stated that in their experience, assistance only showed up half the time. When booked assistance failed to show, this led to difficulties such as being unable to board transport and missed connections. This made it very difficult for some participants to rely on assistance schemes. Another visually impaired train user, for example, described an instance in which pre-booked assistance had failed to show on a late evening journey and they needed to return home because there were no staff at the station at all, and therefore no way of fulfilling their train journey.

Uncertainty as to how the service works and who qualifies. Young disabled people and those with non-visible health conditions, such as mental health conditions, were unsure about whether they qualified for assistance schemes.

> *"You don't want to apply to use it [Passenger Assist (trains)] and then you don't meet the criteria. I don't know how to use it, I don't know anything about it. It needs to be advertised more, to help raise awareness." [Female, 40 – 64, multiple health conditions including mental and cognitive]*

Improvements
Suggested improvements to assistance schemes included:
- Providing a way for users to contact the member of staff who is meeting them, for example via an accessible app or text messaging service
- Providing a channel to request further accommodations or changes during the journey
- Providing easier to understand and more transparent information about how to book and access staff assistance

4 Decision making

Decisions about whether and how to travel (i.e. which mode to use and other factors such as route or length) were the product of an individual's travel needs, views and preferences, as well as their past experiences and the circumstances they faced on a given day. While Chapter 3 outlines the range of past experiences described by participants, this chapter seeks to build on those findings by exploring how these positive and negative experiences informed travel *decisions* in the present.

We explore seven key factors that crucially underpinned disabled people's decisions about whether and how to travel. We look at the following factors in turn:

1. **The fluctuating or recurring nature of a health condition.** Disabled people's travel decisions were informed by whether their symptoms varied significantly and unpredictably, or whether they were constant and predictable.
2. **The need for certainty.** Disabled people very often required a high level of certainty about their journeys, and made travel decisions that gave them a range of guarantees: that they would be able to manage their symptoms; that their journeys would go according to plan; and that their journeys would be physically accessible.
3. **The need for autonomy.** For some disabled people, decisions about whether and how to travel were based on whether they would be able to travel without assistance and with a feeling of control.
4. **The need for high-quality assistance.Error! Reference source not found.**For other disabled people, travel decisions were based on the availability and quality of staff assistance.
5. **The need to manage triggers.** For disabled people with certain kinds of mental health conditions such as PTSD, travel decisions were made in order to avoid psychological triggers.
6. **The visibility of disability and notions of deservingness.** Decisions were often informed by society preconceptions of what disability looks like, of who is deserving of assistance and accessibility adjustments, and of feelings of embarrassment or shame.
7. **The affordability of transport.** Disabled people often preferred more expensive modes of transport such as taxis. Some were able to meet this cost, and others were not, which could leave them isolated.

4.1 The fluctuating or recurring nature of a health condition

For all disabled people, decisions about whether and how to travel were strongly affected by the extent to which their state of health varied. Those whose symptoms fluctuated significantly or unpredictably often made their travel decisions in response to these changes, either choosing not to travel, or travelling in a way that enabled them to manage their symptoms. Those whose health condition affected them constantly or predictably – for example, some disabled people with vision or hearing impairments – tended to make more consistent travel choices, and were more able to take longer or unfamiliar journeys.

Variable and unpredictable symptoms could be attributed either to a *fluctuating* health condition, which was characterised by symptoms that were always present, but which varied in severity and could suddenly intensify, for example during a 'flare-up', or to a *recurring* health condition, which was characterised by symptoms that could come and go, with periods where the individual was not affected at all. For those with a fluctuating or recurring health condition, travel decisions were underpinned by the extent to which their current symptoms were impacting them. Symptoms varied in the following ways:

- **Their severity**, which ranged from having no impact on travel to preventing any travel (or fulfilment of other activities such as work or basic daily tasks). For example, some of those with anxiety said that if their anxiety was less severe or not present at all, they were able to travel confidently (or at least, with the right provisions – see Section 4.2) but if they were in a highly anxious state, they would not be able to travel at all.

- **Their frequency of occurrence**, which ranged from impacting travel only once or twice a year, to several times per week. For example, a participant with epilepsy indicated that they would only take the decision *not* to travel if they were recovering from a bad seizure, which would not happen more than a few times each year. This was in contrast to participants whose conditions caused physical discomfort that prevented them from travelling most days of the week, which was mentioned by those with conditions such as arthritis.
- **Their duration of effect**, which ranged from a few hours to several weeks or months. For example, while participants with physical health conditions typically experienced flare-ups lasting a few hours or days, a participant with rheumatoid arthritis said their worst flare-ups had lasted around two months and prevented them from travelling for most of that time.

For those with mental health conditions, a range of psychological states could impact the decision to travel. Examples included general feelings of depression, low mood or a lack of motivation; heightened anxiety or social anxiety; feelings of unsafety in relation to the possibility of experiencing a health-related injury or accident; feelings of personal safety in relation to other passengers; and high susceptibility to triggers (see Section 4.5), which typically included having to deal with uncertainty or social interaction. When affected, such states increased difficulty of travel and, in some cases, prevented travel entirely. In other cases, participants decided to travel only if certain conditions were fulfilled. Such conditions will be explored throughout the rest of this chapter.

> *“If my anxiety is so bad, I won't even open the front door […] I don't have confidence, especially when I've [already] been out. I feel safer in my own house than outside.” [Female, 18-39, multiple health conditions including mental and physical]*

For those with a physical health condition that limited mobility, stamina or dexterity, periods of heightened physical symptoms such as pain, fatigue or discomfort made it difficult or impossible to travel. In some instances, symptoms could occur or become worse without warning. In others, they were triggered, for example, by walking too far or by something more specific such as high atmospheric pressure. Following the onset of such symptoms, it could be necessary for participants to cancel their travel plans to focus on rest and recovery, sometimes for days at a time. At other times, journeys could still be fulfilled but only by taking private transport, as this would involve a much lower degree of physical exertion than public transport.

> *“If I was having a bad flare-up, I wouldn't go anywhere anyway because I'd be in too much pain.” [Female, 40-64, physical health condition]*

For those with a physical disability that limited digestive, bowel or bladder function, periods where they experienced a greater severity of symptoms made travel difficult or impossible. Factors that contributed to this included needing to use the toilet very frequently and being unable to maintain energy during periods of heightened malabsorption.

Pen portrait: the need to manage a fluctuating health condition

Mary's decisions and whether and how to travel vary in line with her fluctuating state of health – on 'good days' she travels confidently but on 'bad days' she might not be able to travel at all. She is in her seventies, is in retirement and lives in a small town. As she cannot drive, she relies on public transport or lifts from family and friends to travel.

Mary's health condition limits her digestive, bowel and bladder function, and she has an ileostomy. Due to her health condition, Mary cannot retain fluids. This makes it difficult for her to maintain energy and means that she needs to use the toilet frequently. On 'good days', this does not prevent her from travelling, so long as she takes the right precautions (which include first planning her journey to ensure she will have easy access to toilets and then bringing toiletries and a change of clothes on the journey). However, on 'bad days', she can feel light-headed, fatigued and needs to use the toilet frequently. This means that she cannot travel, or only with a lift.

"On a good day I'm out and about and I'm doing things, but everywhere I go I have to take a change of clothing and I have to have my supplies in my bag."

"A bad day is running to the loo all the time because the stoma works so much, and I'm losing so much fluid through it […] you lose confidence, you don't want to go out because you're very frightened of what might happen."

4.2 The need for certainty

Some disabled people required certainty about particular aspects of their journeys and would only decide to travel under very specific conditions, that will be explored in this section. Travelling with certainty was important because the transport system often did not provide participants with the necessary conditions to manage their disability while travelling and because, if something did go wrong, the implications could be very severe. Participants achieved a sense of certainty by engaging in advance and meticulous planning, or by taking provisions to manage their health condition at key stages before or during the journey. Four broad prerequisites to travelling with certainty are explored in more detail below.

Guaranteeing the ability to manage time-bound symptoms

For those with a physical health condition, decisions about whether and how to travel were based on a need for certainty that they would have the necessary time and conditions to manage their symptoms for the duration of the journey. This could mean limiting the duration of their journey or the amount of time that they were under physical exertion; or ensuring they would have access to toilet facilities, food and shelter.

For those with limited mobility, stamina or dexterity, it was essential to manage physical exertion. For example, for those with joint conditions, standing for too long could lead to unbearable pain. When travelling by plane, a participant said they would only take two-hour flights, as sitting in one position for any longer would cause pain lasting days. They said having extra legroom would alleviate this, but was unaffordable, and so this limited where they could fly to on holiday. It could also be essential to travel and return home again before pain medication wore off, which could be very limiting:

> *"Before I have any long journey at all, I have to take a large dose of morphine and diazepam, which only lasts at best six hours. Two hours of that six hours, it puts me into an instant sleep… If I had to go somewhere a bit further away than my normal [journeys], I'd have to wake up at, say, six o'clock, take the morphine and diazepam, go to sleep for a couple of hours, then wake up. At the end of*

> *that four-hour period I would have to be where I was, otherwise I couldn't cope with the pain." [Male, 40-65, physical health condition]*

For those with limited digestive, bowel or bladder function, it was essential to plan around the availability of toilets and food, or exposure to extreme temperatures. Precautions included using the toilet immediately before any journey; only taking routes with access to toilet facilities or shelter throughout the journey; or travelling with provisions such as a change of clothes, toiletries or food. This could be very limiting, for example, restricting participants to travel from bus stops in close proximity to a toilet or journeys lasting no more than 2 hours if toilet access was not guaranteed. The quality of facilities could also be essential. For example, a participant said their requirements included adequate washing facilities, space to change and clean facilities, as their immunosuppressant medication left them vulnerable to infection. They described an instance where they cancelled a holiday after a change to the facilities advertised on their overnight train:

> *"We had it all booked… for going on the new super trains… and they went and let us down because they didn't get the cars in. [The] new carriages have a toilet and a shower in the cabins, whereas the old ones only have a toilet per carriage […] My whole holiday was cancelled because they had to use the old carriages which didn't fit my needs." [Male, 65+, physical health condition]*

Managing food requirements was also important. For participants with malabsorptive conditions, booking a first-class train ticket could be essential for taking longer journeys, as it guaranteed the availability of a meal. Contrastingly, for a participant with incontinence and a mental health condition, eating while out was *never* an option, as it would trigger the need to use public toilet facilities, which was itself a mental trigger. Another participant with an ileostomy would never wait at a bus stop longer than 30 minutes, or they would become too cold to regulate their body temperature and would have to return home and avoid travel for the rest of the day.

Guaranteeing that journeys go according to plan

For those with cognitive or sensory impairments, or anxiety-related health conditions, decisions about whether and how to travel were based on a need for certainty about where they were going, the information they would have access to, or certainty that the journey was going to plan (for example, certainty they had caught the correct bus or train). To achieve this, participants took the following provisions:

- **Advance preparation**. For example, a participant with a cognitive impairment always 'studied' their route in advance as they struggled to understand transport timetables.
- **Arriving early,** to avoid missing the arrival of a bus or train
- **Avoiding any travel by train**, as changing platforms involved too much uncertainty.
- **Only taking simple journeys**. For example, a participant with a cognitive impairment only undertook straightforward journeys without too many variables at play (for example, without lots of mode or platform changes), to avoid missing or forgetting crucial information after becoming cognitively overwhelmed.
- **Guaranteeing access to journey information via preferred mode**. For example, a participant with a hearing impairment would only travel by airlines that provided journey information via screens, as they could not hear spoken announcements. When travelling by bus, a visually impaired participant would only use routes with full mobile signal, to ensure the functionality of their accessible travel app. This was because they could not hear announcements over external noise and if the driver

accidentally told them to get off at the wrong stop, *and* this stop lacked mobile signal, they would be stranded without help.

Pen portrait: the importance of travelling with certainty for those with anxiety

For Mark, the decision to travel hinges on having certainty that he will be able to get to his destination on time. It was essential to be certain of this both before leaving home, and throughout the journey. Mark is in his twenties and lives in a small town. He does not drive. In a typical week, he uses the bus to shop for food and to visit family. On the bus, he can experience anxiety in response to specific triggers including overcrowding, not having access to live journey information and being delayed. When heightened, his anxiety can trigger a panic attack but with the right precautions, he travels confidently.

To limit his anxiety, Mark always arrives at the bus stop early, which ensures he will not miss his bus. At the bus stop, he uses an app to stay informed about bus times and the current location of the bus he is waiting for. He cannot fall back on other passengers or staff for this information as social interaction is a psychological trigger. This means he must charge his phone in advance. However, if Mark's phone runs out of battery when waiting for a bus, or if he cannot board an uncrowded bus, he will return home and forego travel entirely:

"If it was before I was on the bus, I'd go home and calm down if I didn't have the ability to know where or how late it was going to be or if I thought it was coming and I got too panicked. If it was to do with the bus being too full, if there were too many people there and it got my anxiety going, then every time it would be leave the bus and either get the next one or not be able to get on the bus that day and not go."

Guaranteeing physical accessibility

For those with a physical health condition that limited mobility, stamina or dexterity, decisions about whether and how to travel were based on a need for certainty that the journey would be physically accessible to them. To achieve this, participants took the following provisions:

- **Limiting the distance they walked**. For example, a participant who preferred driving only did so if parking in close proximity to their destination was guaranteed. For this reason, they would not risk driving to locations that were very likely to be busy, for instance driving to London, and this forced them to sometimes use modes that were less accessible to them, such as trains.
- **Travelling during non-peak hours**. For example, a wheelchair user who did not drive and who lived in a rural location said taking the bus was the only mode they could use independently. However, during peak hours, it was too crowded for them to get on. They also needed to travel in the early morning, as their local bus service was very limited. If they didn't get on, they would need to request a lift from a friend or pay more to travel by taxi.
- **Pre-booking assistance**. A participant said that pre-booking airport assistance was essential as they would be provided with a wheelchair and wouldn't risk airlines damaging their personal one in transit, which had happened multiple times in the past. Furthermore, a visually impaired participant said that while pre-booking had not fully guaranteed them assistance when travelling by train in the past, it gave them evidence to fall back on in the event of failed assistance. For example, they said that if they arrived at a train station later than the time at which they had booked assistance, as a result of failed assistance on an earlier leg of the journey, staff would be more likely to assist them if they could show proof of the booking:

> *“That's why I like to book assistance […] then I can say to them, 'Well, look, it's Mr Smith. I should have been here an hour ago. There was a mess up at point A, but I'm here now, can you help me?' They're normally fine with that because you've booked in the first place.” [Male, 40-64, visual impairment]*

- **Checking accessibility of train stations**. For example, if it was not possible to book a direct route some participants would not travel at all. For others, it was essential to know that any stations with staircases had a working lift or, if forced to use the stairs, to know there would be sufficient time to take it slow. If accessibility was not guaranteed on the fastest route, another participant chose to take much longer journeys to avoid inaccessible train stations.

> *“Where are [there] connections involved? I'll go on to real-time trains and have a look at the diagram and think, right, oh no, I can't change there because it gets in on platform 2 and leaves on platform 11. So I'll have a look at another journey and so on and so forth.” [Male, 65+, physical health condition]*

4.3 The need for autonomy

Some disabled people decided whether and how to travel based on whether they would be able to travel autonomously – i.e. without assistance, and with a feeling of control. This was in contrast to others who made decisions based on the availability of assistance and support, which is discussed in Section 4.4. Travelling autonomously was not always a prerequisite to travelling but was always important for travelling with confidence. This section explores the factors that afforded participants a sense of autonomy.

Driving or being driven by a trusted companion

Some disabled people preferred the feeling of control when driving or being driven by someone they knew, as opposed to taking public transport or a taxi. This was true for disabled people with a wide range of health conditions and impairments.

For those with physical health conditions that limited mobility, stamina or dexterity, the decision to travel by car was often motivated by a need to control their physical symptoms, in three ways. Firstly, travelling by car put them in control over the extent of physical exertion they experienced, for example because there was no chance of them becoming delayed or disrupted on public transport and having to stand for a long period of time. Secondly, it meant they could return home without any delay if their symptoms suddenly got worse. Thirdly, it put them in control of their immediate physical environment; for example, by prevented them from having to manoeuvre their mobility aid in confined spaces.

> *“There's nothing I've got to listen out for. It's just I've got complete control. If I've gone the wrong way, then I can correct it. I'm not stuck for an hour where I've got to change at a station or something like that, so yes. Almost everything that makes me not confident with other modes of transport is what's great about driving.” [Male, 18-39, physical health condition]*

Participants with a physical health condition that limited digestive, bowel or bladder function typically preferred travelling by car. This was because they could easily bring provisions with them (see section 4.2) and if they experienced an accident, they would have the freedom to deal with this in isolation from anyone else.

> *"I feel as though I can escape. I'm in a little portable house and it's got my own things in it and I don't need to worry […] I am safe." [Female, 65+, multiple health conditions including physical and mental]*

Some participants with mental health conditions also preferred car journeys to public transport as they involved fewer triggers and for those with cognitive or hearing impairments, they involved less reliance on written information or announcements. Finally, a participant with a hearing impairment never travelled by taxi unless this was the only option because they struggled to communicate with the driver and so wouldn't easily know if they were being driven in the wrong direction.

A long history with disability

Participants with severe congenital or long since acquired physical health conditions or visual impairments typically stood out as having a higher sense of autonomy than participants who had more recently been disabled. Despite facing profound barriers, such participants tended not to struggle to use public transport and had extensive knowledge of what to do in the event of issues such as journey disruption and discrimination, as well as the confidence to act on this knowledge.

> *"You're much more confident than a person who's had a very serious accident or illness and become disabled, especially later in life. [It is] very hard for them to come to terms with, whereas I watch somebody with spina bifida or something like that; they've grown up with it." [Female, 65+, physical health condition]*

They attributed this to two key factors. Firstly, having grown up with their disability meant they had a long time to become experts in managing it when using public transport. Secondly, they tended to be experts on issues affecting all disabled people because they had either dedicated themselves to working in the field of disability or were otherwise very active in the disabled community. This afforded them an extensive knowledge of their rights and the assistance or journey assistance tools available to them that, when taken advantage of, could help them to overcome many of the barriers they faced.

> *"You've got to take into account the personality of the individual. So I'm quite a confident person anyway, and I don't have an issue with challenging people, but I know an awful lot of people that are very, very different." [Male, 40-64, visual impairment]*

4.4 The need for high-quality assistance

Some disabled people made decisions about whether and how to travel based on the quality and availability of assistance (this was in contrast to those whose travel decisions were underpinned by the need for autonomy – see section 4.3).

Some disabled people would only travel if the assistance they needed could be guaranteed. A participant who used community transport would only travel with a driver they knew, or else they felt the driver could not be relied on to notify them when their stop had been reached. Another participant avoided taxis due to experiences with drivers who lacked disability awareness and therefore awareness of the reasonable adjustments they required. The assistance dog users we interviewed would also book taxis in advance so they could inform the operator that they travelled with an assistance dog and therefore guarantee they would not experience an (illegal) service refusal.

> *"I've had other visually impaired people tell me they've struggled to use taxis because the driver says, 'Oh, a guide dog. I can't have that.' I say, 'Well, tell them before then – while you're booking it." [Female, 40-34, visual impairment]*

Past experiences of high- or low-quality assistance often informed decision making. One group of participants who required assistance to travel by plane flew with confidence, because the quality of assistance they had experienced was high. A participant with a physical health condition was able to fly with full confidence, even during an intense flare up, due to the degree of assistance and empathy shown by staff. On the other hand, she generally chose to avoid bus journeys due to the impatient and unsympathetic attitude she had experienced from drivers.

> *"I can go abroad confidently but I can't catch two buses to go to my friend's confidently." [Female, 40-64, physical health condition]*

One aspect of high-quality assistance was staff knowing how to ask a disabled person if they needed assistance, and knowing how to react if people felt offended by the question:

> *"I would expect companies to provide staff training in how to approach someone who may need help and going up to speak to them and saying, 'Do you need any assistance?' and how to ask for that, and expect that some people might snap and go, 'No, why do you ask?' and knowing how to manage that." [Male, 40-64, visual impairment]*

Other participants made decisions about whether and how to travel based on expectations around the way that staff would conduct themselves generally, rather than when they required assistance. A participant with an ileostomy felt 'singled out' by security staff every time they went through airport security scanners as their stoma ring was always flagged up. Though staff had been understanding, she described the experience of first being pulled aside and then needing to explain her stoma to them as overwhelming and stressful. As discussed in Section 3.3, some disabled people had negative experiences following instances where bus drivers had not waited for them to sit down before driving off. As a result of this, some participants avoided buses entirely for fear of being in pain, discomfort or injury. Finally, for participants with visual, hearing or cognitive impairments that made it difficult to communicate, decision making was underpinned by the need to avoid situations in which the quality of staff assistance could not be relied on. A participant with a visual impairment only ever travelled with a specific local taxi company they knew well, as they felt not all taxi drivers could be trusted to conduct themselves professionally.

> *"It's just staff training really, to know how to assist somebody with poor vision. Not to ask them questions as you're going along about when did you lose your sight? How much can you see? How many fingers am I holding up? Are you really blind or just faking it? I know these sound a little bit extreme, but they're all questions that I have been asked before, many times […] saying that all visually impaired people have to sit in the back, what it's implying is that we're a junior, we are of diminished responsibility. We're not actually a fully-fledged adult because of our disability." [Male, 40-64, visual impairment]*

Pen portrait: the inaccessibility of staff interaction for those with hearing and cognitive impairments

Freya's decisions and how to travel hinge on a need to use a car or train, rather than taxis or buses, which she actively avoids. In large part, this is because she finds interacting with staff difficult, and finds the provision of journey information on trains easier to use and more effective. Freya is in her thirties and lives in a small city.

Freya's cognitive impairment makes it difficult to first understand and then remember written information, particularly via formats such as LED scrolling screens. Her hearing impairment and cognitive impairment makes it difficult to hear and then process audio announcements and speech, which means she must rely on lip reading. When travelling by train, these barriers are more easily overcome as she can rely on live journey information on her phone (which she finds easier to understand than audio-visual information) and because it's easy to have face-to-face communication with staff, unlike on buses.

When travelling by bus, she finds live journey apps to be unreliable. This could be overcome with help from bus drivers, but they are always sat behind a screen and facing away from her. In her experience, they have also been impatient and unwilling to repeat themselves. This makes it very difficult to stay updated throughout a bus journey. Similarly, she avoids travelling by taxi as the driver is her only source of information and communicating with them is difficult.

"I actively avoid buses […] I really don't want to interact with bus drivers […] They are really irritable so I'm not wanting to. If I have a question, I'm not going to ask, I don't want to ask it. I've had some of them shout before because I've not heard and then I've done the wrong thing."

"Taxis I avoid because I don't know what's [laughs] going on! It's this feeling of not really knowing what's going on and not feeling like I can ask."

4.5 The need to manage triggers

We use the term trigger to refer to anything within the travelling environment that prompted an involuntary, adverse psychological reaction, as a function of the way that a trigger interacted with the participant's mental health condition. Some disabled people made decisions about whether and how to travel based on the need to manage their triggers, or to avoid being triggered entirely. Managing or avoiding triggers was important due to the adverse reactions they could prompt. When triggered, reactions included feeling an overwhelming sense of anxiety or stress – which could, for some, result in a panic attack – or experiencing a flashback (for those with PTSD). Below, we explore two common types of situations in which participants described being triggered.

Firstly, participants with severe social anxiety could be triggered by the need to be among or interact with strangers, including other passengers and staff. This group differed from some other participants with mental health conditions, for whom social interaction with strangers triggered a less significant degree of anxiety that could be overcome and did not impact on decision making. By contrast, those with severe social anxiety could experience overwhelming stress, anxiety or a panic attack as a result of needing to interact with strangers and so took precautions to avoid this. Such actions included buying tickets online or via contactless and checking-in online; wearing headphones so that strangers would be less likely to engage with them; sitting away from other passengers, for example, in single seating; travelling with someone they knew; avoiding travel on crowded transport; or avoiding travel by public transport or taxi altogether. By way of example, a participant with severe social anxiety avoided any transport by bus or taxi due to the need to interact with the driver and chose to travel with their partner whenever possible, as this reduced the chances of unexpected social interaction:

“The social anxiety, I really struggle with groups of people, parties or engaging with people, talking […] I'm not comfortable knowing what to say to people, and just generally don't like the attention […] I wouldn't like to travel alone usually on public transport because it would mean I would be sitting alone and there would be an empty seat that someone could sit in next to me, or I might need to sit next to someone, and I'm not really keen on that in case they try and talk to me.” [Male, 18-39, mental health condition]

Secondly, some participants with severe anxiety, schizophrenia or PTSD could be triggered by feelings of unsafety in relation to other passengers. This occurred under specific travelling conditions such as being on public transport when crowded, travelling in the dark, being in the presence of rowdy, loud or violent passengers, being in the presence of male passengers (for some female participants) or travelling by taxi (and therefore having to place their trust in a taxi driver). These triggers were typically linked to trauma or abuse participants had experienced in their past. Actions taken by participants to limit or avoid interaction with these triggers included – again – sitting away from other passengers, avoiding crowded journeys, avoiding public transport or travel by taxi and travelling with someone else; but also avoiding travel at night or via large cities. A female participant with anxiety found the need to interact with male strangers triggering, as a result of abuse she had experienced in her past. When triggered, she could experience overwhelming stress, anxiety or a panic attack. To manage this, she avoided ever speaking to male strangers, including both passengers and staff. When travelling by bus, she preferred to travel with someone else and usually tried to find seating as far away from others as possible, so that she could ‘hide’.

Pen portrait: the importance of avoiding triggering situations

Vincent’s decisions about whether and how to travel hinge on completely avoiding any situation that might trigger his PTSD. Vincent is in his forties and lives in a town. He fulfils his commute and most other journeys by car. He can be confident using public transport at times, but generally feels more relaxed when driving.

Since he developed PTSD, Vincent can experience anxiety and flashbacks in response to feelings of unsafety. Situations that can contribute to feelings of unsafety when travelling include travelling late at night and travelling in large cities, which are likely to be crowded. This is a change to his lifestyle before developing PTSD, when he lived in a large city for several years.

Though Vincent says he’s not experienced a flashback while undertaking a journey by public transport, the potential of this happening is enough to prevent him from travelling late at night or via large cities and, as a result, his overall extent of travel by public transport is limited.

“I've got a lot of triggers, a lot of flashbacks […] if I was on a late-night train, I might start to imagine that I was being followed […] for the last five years I've only been to London once, and that was for a hospital appointment. I just avoid things. That health condition has affected my lifestyle.”

4.6 The visibility of disability and notions of deservingness

For some disabled people, decisions about whether and how to travel were underpinned by societal preconceptions about what disability looks like; who is deserving of mobility aids or reasonable adjustments when travelling (such as additional space or access to priority seating); or the stigma that could accompany the uptake of such adjustments.

Two cross-cutting barriers decreased participants travelling confidence. Firstly, when discussing their travel decisions, participants echoed wider societal misconceptions about disability and deservingness. This perhaps indicated that they had themselves adopted commonly held misassumptions about disability and projected these beliefs onto themselves in a way that limited their options for how to travel. For example, they described themselves as being ‘too young’ or ‘not disabled enough’ to take up a mobility aid or reasonable adjustments, or they worried that ‘someone else needs it more than me’. Secondly, in other instances, participants expressed fear of judgement from other passengers who might consider them to be underserving, even if the participants themselves showed no evidence of believing this.

Such barriers stood out the most in the experiences of two groups. Firstly, those with non-visible disabilities often lacked confidence taking up reasonable adjustments. Secondly, among those with recently acquired health conditions, some participants appeared to be in the process of coming to terms with their disability and the extent to which reasonable adjustments would benefit them.

Such barriers underpinned travel decisions in the following situations.

When using a mobility aid. One group of participants with health conditions that limited mobility, stamina or dexterity did not use a mobility aid, or struggled with making the choice to use one. They put this down primarily to stigma – namely that the belief they were ‘too young’. For example, a participant with a physical health condition chose not to book airport assistance, despite being unable to walk without support:

> *“I hate the idea of being pushed in a wheelchair. I don't feel as if I'm ready for a wheelchair as yet. But in America they always have the electric buggy, which kind of I don't feel as bad. I feel as if everyone's looking at you, saying, 'Why have you got that? Why are you sitting in that? There's nothing wrong with you', whereas you just don't have that in America because… there's hundreds of them driving about. So it's just the norm over there whereas you're made to feel like a bit of a leper over here.” [Female, 40-64, physical health condition]*

For another participant, coming to terms with using a mobility scooter took a long time but, once they did, they came to value the freedom and autonomy it offered them:

> *“It took me four years to accept the fact that I wasn't going to walk properly again ever […] The scooter, it felt like accepting an old person's alternative […] I said, 'No, that's not for me, not for me. No, I'll walk, I'll walk,' and, of course, I couldn't […] Once I accepted it and didn't feel humiliated by it, well, when I'm just on a smooth pavement, wind in my hair, I'm free.” [Female, 65+, physical health condition]*

Finally, another participant described avoiding the use of a walking stick to manage the perceived stigma that could accompany this. Due to their mental health condition, they experienced social anxiety when interacting with others and worried they were looking at her, which could trigger a panic attack. Due to their physical health conditions, they could not walk unassisted and without frequent stops or they would experience breathing difficulties and pain. They described travelling with an umbrella, rather than a walking stick, to ‘disguise’ the fact that they had a physical health condition.

> *"I consider myself to be relatively young, so I don't want to walk about with a stick as yet, so I use a large umbrella to disguise. That acts as the walking stick for me, so I carry that all the time […] I normally try to stop, pretending that I'm looking at a fruit stall or checking out a shop or waiting at the bus stop to not make it quite so obvious."*

When using an accessible toilet. While no one said they *chose not to* use accessible toilets, participants with non-visible health conditions often struggled with deciding to use them in the presence of others. This was because it was not obvious to other passengers why they needed it. They feared being unfairly judged or called out for doing so, which had happened in the past – sometimes from others who believed themselves to be more deserving such as mothers with babies or wheelchair users.

> *"They look at you and you know what they're thinking; why are you using this toilet, because there's nothing wrong with you? You're just using it for convenience." [Female, 65+, physical health condition]*

When asking for a seat. Disabled people with a range of different health conditions or impairments said they did not have the confidence to ask another passenger to vacate a seat and some found this to be psychologically triggering. This was particularly the case among younger participants and those with a non-visible disability. For a participant with epilepsy, having a priority seat on the bus was important as the additional space meant they were less likely to injure themselves in the event of a seizure. However, they never asked other passengers to vacate a seat for fear of judgement.

These experiences stood in contrast to those of a participant with a highly visible physical health condition, who had been disabled their whole life. When travelling anywhere, they would use multiple mobility aids. They travelled confidently and rarely needed to ask for help, or for another passenger to give up their seat. This was, perhaps, because they met societal preconceptions about what disability looks like.

> *"People are very, very good: going across to hospital [on the London Underground], I've got my mobility aids and, they will say, 'Oh, would you like a helping hand?' I say, 'No, I think I'm all right, but thank you for the offer.' Invariably, especially with young men, they will stop at the top of the steps and they wait until I've got up there […] as if, 'She doesn't want a hand, she's an independent lady but we're going to watch and make sure she's all right.' I think that is lovely." [Female, 65+, physical health condition]*

When another passenger is in need. Participants often said they would forego the relief that taking up a reasonable adjustment offered them if they perceived another passenger to be in greater need. For example, in the presence of someone they thought was older or 'more disabled' than them, or for passengers with pushchairs. A participant also highlighted that for some disabled people, it can sometimes feel easier to forego a reasonable adjustment than attempting to communicate to other passengers – including other disabled passengers – why they need a reasonable adjustment just as much or more than them.

Without a journey assistance tool. Some disabled participants who used journey assistance tools remarked on their usefulness, while some of those who did not indicated that having nothing to indicate they had a disability led to difficulties.

> *"I've got no blue badge or walking stick or anything to tell anyone that I've got a problem." [Female, 18-39, physical health condition]*

A participant expressed that although a journey assistance tool can draw unwanted attention to a disability, the benefits can outweigh this.

> *"In a way it tags you as disabled, but most people don't mind if it's subtle, wearing a lanyard, wearing a badge or something. I carry a little card. I don't really have to use it in most of the places, but it says, 'I can't wait.'" [Male, 65+, physical health condition]*

4.7 The affordability of transport

For some disabled people, decisions about whether and how to travel were based on their ability to afford the modes of transport that were accessible to them. Where this was the case, participants strongly preferred using private transport. This was due to the physical inaccessibility, or the triggering nature of public transport (see section 4.5). The range of alternative mode choices cited by participants included driving, being driven by someone they knew, using a taxi or community transport. However, although these transport modes better met participants needs, they usually came at a premium that not all participants could afford. Participants fell into the two groups outlined below.

Regular users of private transport

Participants in this group regularly chose to use the modes of private transport that were most accessible to them, such as driving. Some participants could afford to do so comfortably, whereas others struggled financially but also had no other choice.

> *"There's no way I could go to a shop on a bus and carry home shopping […] I just have to take it on the nose, if it's going to cost me money to park, then this is what I do […] I've a very meagre income, I live on pension income, it's a significant factor." [Male, 65+, physical health condition]*

In some instances, participants could only afford to use private transport regularly by making financial sacrifices. A participant with arthritis described his typical week as *ideally* involving three shopping trips and at least two visits to his disabled elderly father. As his local bus stop was more than half an hour away on foot – an impossible distance for him to walk – his only option was driving. This meant that due to the cost of driving, he often needed to limit his shopping trips to one per fortnight in order to keep visiting his father regularly.

Occasional users of private transport

Participants in this group less regularly chose to pay for the modes of private transport that were most accessible to them. This was because they could not afford to do so, which meant they relied more heavily on their family and friends for lifts or were forced to use public transport. For this group, there was a clear relationship between their disability and the unaffordability of private transport. For example, having a disability meant that they were long term unemployed or could not drive, but also could not afford to pay for transport regularly.

Pen portrait: the unaffordability of accessible transport

For Christopher, decisions and how to travel hinge on the availability of the transport options that are affordable to him. Christopher is in his fifties and lives in a rural village. He is in long-term unemployment as a result of being unable to find work that is compatible with his visual impairment. His wife also does not work, for similar reasons. In a typical week, Christopher travels by bus to a nearby town (for example, for shopping) or his wife drives him.

“Because of my illnesses, I don't order a taxi just out of nowhere; because we don't work, with our mobility, I can't afford to go in a taxi.”

If Christopher wants to travel independently, he must do so by bus. This is because other modes of transport are not affordable to him, whereas his bus pass enables free travel. He likes to pursue hobbies outdoors but cannot do so independently because there are no bus routes that would get him there. Alternative modes of transport include taxi and a local community transport service. However, both are unaffordable to him which means that he is reliant on lifts from his wife.

“They have a community transport service – door to door that goes around […] I could chase them up one day, asking if they could sort out transport and they could take me to certain places [not accessible by bus], but it was just coming up, they were too expensive, so I didn't bother with it.”

5 Discussion

The ITS evaluation is ongoing, with a second round of extensive quantitative and qualitative data collection in 2023, and a final evaluation report due to be published in 2024. The current report, which draws on data collected in 2020 but has been written in early 2023, offers us the opportunity to pause and reflect on the evaluation: on what has been learned so far, and where further research is required.

This chapter begins with a discussion of some of the emerging high-level policy implications from the research, although a fuller discussion of implications will be included in the final evaluation report. It then considers some key areas where more research is needed, either because the scope of the ITS evaluation is necessarily limited, or because the emerging findings have raised new and important questions.

The importance of wider social factors

No area of public policymaking operates in isolation, and transport is no different. For all of us, our transport needs and experiences are embedded within the rest of our lives: where we live, who we live with, our employment, our incomes, and more. The ITS aims to create a transport system that offers *equal* access to disabled passengers, but to some extent it is not possible to ensure equal access without addressing some wider inequalities in other areas of our lives.

There are complex interactions between disability, employment, income, and transport. Disabled people are less likely to be employed,[a] and people who are not in work have fewer financial resources. Disabled people earn less, on average, than non-disabled people.[b] Disabled people also face additional costs, such as care and medication, which reduces their disposable income.[c] People with fewer financial resources have less access to the transport system, and people with less access to the transport system may find it harder to access employment.[d] Conversely, those not in work may have less need to use the transport system. All of these interactions are relevant to an assessment of whether disabled people truly have *equal* access to the transport system, but not all of them can be influenced by transport policy.

Disabled people also face stigma and discrimination, as shown in some of behaviour of transport staff and passengers described in this report. Stigma can also be internalised, and disabled people can feel shame or embarrassment when using the transport system. Changes to the transport system alone cannot address these issues.

Consistency and diversity

The research conducted to date shows that for most disabled people, most of the time, the transport system works well. When facilities are available and functioning, when information is accessible and accurate, when services are on time and not too busy, when staff are helpful, and when other passengers are considerate, disabled people can travel with confidence and ease. But while non-disabled people can be inconvenienced or frustrated by negative transport experiences such as delayed services, for many disabled people the implications are much more serious.

These findings emphasise the importance of providing *consistency*. It is crucial that services are regular and reliable, and are not overcrowded. And it is crucial to find ways of reassuring disabled people that journeys will go to plan, including accurate and accessible information about the availability of facilities, and ongoing information throughout the journey.

A further consideration for policy makers is the substantial *diversity* of needs and preferences amongst disabled people. There is rarely a one-size-fits-all approach, from options for buying tickets, to physical infrastructure, to ways of accessing or presenting real-time journey information. The transport system therefore needs to provide a consistent level of service while simultaneously catering to a wide range of needs.

Areas for further research

The ITS evaluation collected a wealth of quantitative and qualitative data in 2020, and more is to come in 2023. However, the current report has highlighted some key areas where further research would be helpful, but are beyond the scope of the ITS evaluation.

Firstly, there are important voices that have not been heard from. The current report is based on 40 qualitative interviews with disabled people, but not all disabled people are able to take part in such interviews, at least without certain accommodations. Most obviously, people with certain cognitive impairments and/or communication difficulties were not able to take part. There were also some groups who were not eligible to be interviewed as part of the current research: children and young people, and carers of disabled people. Lastly, there were people who were simply very unlikely to have been included in the sample, such as people living in institutions. Given the level of diversity in needs and preferences amongst those we did interview, it is likely that these groups can help us reach new insights.

Secondly, although the current report aimed to explore the lived experience of disabled travellers by using detailed qualitative interviews, it did not include any direct ethnographic or observational evidence. It would be valuable to accompany disabled people on their journeys to directly observe their experiences. This would enable researchers build a fuller picture of the barriers and enablers to achieving equal access to the transport system.

Technical appendix

This component of the research aimed to understand disabled people's experiences of travelling using different transport modes. In-depth qualitative interviews were the chosen method as they enabled us to gain a rich and detailed understanding of disabled people's experiences of travel, the facilitators and barriers to travel, and the interventions required to improve disabled passengers' experiences of travel.

Fieldwork for this component of the research was conducted in August and September 2020. In total, 40 participants were interviewed.

1. Sampling

The sample for the recruitment of participants was drawn from early respondents to the first wave of the ITS Panel Survey. Survey respondents were asked if they would be willing to take part in follow up qualitative interviews and were invited to leave their contact details, then followed up with a recruitment call (see Recruitment process).

In order to ensure a diversity of views and experiences, a purposive sampling approach was taken. Participants were selected based on primary criteria agreed with DfT, namely type of disability, age and type of travel, with quotas set for key characteristics. These criteria were agreed in order to capture a range of experiences, but also to ensure that key elements of the travelling experience linked to themes of the ITS, were included.

Table 1 below shows the primary criteria, minimum quotas and the number of interviews completed in each category. As is evident from the table, all of the minimum sampling quotas were met apart from for those who do not travel at all by public transport. It was difficult to recruit participants in this category because of the low number of overall survey respondents who did not use public transport.

Table 1: Sampling quotas based on primary criteria

Characteristics	Minimum quota	Completed
Type of disability[e]		
Multiple impairments	10	26
Mobility related	12	25
Sensory related – hearing	3	3
Sensory related – vision	3	6
Cognitive	5	8
Other conditions or impairments[f]	12	30 (14 of which are mental health)
Age		
18-39	10	10
40-64	10	16
65+	10	14
Type of travel[g]		
Assistance dog users who take taxis	2	2
Wheelchair users who take buses	2	2
Users of Changing Places facilities	2	5
Users of multiple modes	10	26
Does not travel on public transport	5	3

Secondary sampling criteria were also monitored during recruitment to make sure that the sample achieved range and diversity against each criterion. While every effort was made to get a spread of participants across the characteristics, most participants were of white backgrounds, confident at travelling, based in England and in urban areas, reflecting the overall numbers within survey respondents. Table 2 below shows how many interviews were completed for each secondary criteria characteristic.

Table 2: Sample monitoring of secondary criteria characteristics

Characteristics	Interviews completed
Gender	
Male	18
Female	22
Experience of travel by air and water[h]	
Has travelled by air	15
Has travelled by water	11
Not travelled by air or water	18
Ethnicity	
White	36
Other ethnic background	3
Not provided	1
Confidence Level	
Confident	27
Somewhat confident	7
Not confident	4
Did not travel	2
Type of Area	
Rural	11
Urban	29
Region of UK	
England	27
Wales	8
Scotland	5

Throughout recruitment, frequency of use of each mode of transport – bus, train, taxi, car – was also monitored to ensure a spread of people who used each mode frequently and infrequently[i].

2. Recruitment process

Telephone recruiters contacted the participants in the recruitment sample to invite them to take part in the interview. To guide them with recruitment, telephone recruiters were provided with detailed recruitment instructions, a recruitment script, screening questionnaire and a recruitment log to work to, which contained contact details of participants as well as their specific characteristics.

During recruitment, it became evident that the sample did not contain enough assistance dog users that take taxis. To recruit the two participants needed in this category, we reached out to the Royal National Institute of Blind People (RNIB), who recruited both participants and passed their contact details to the research team.

Recruiters also logged when special arrangements were needed for people who suffer from hearing loss, have a visual impairment or if participants wished to have someone to support them during the interview (paired interview) or someone to take part in the interview on the participant's behalf (proxy interview). In total, we conducted three paired interviews and no proxy interviews.

All those recruited were sent confirmation emails, which included a participation information leaflet outlining what the research was about, what taking part involved, how the data collected was to be used and contained a link to the GDPR-compliant study web page. The information leaflet was also available in large print.

Each participant was offered a £40 gift voucher as a thank you for their time and to offer a small incentive to secure their engagement.

3. Conduct of interviews

Interviewers used a topic guide to lead the discussion. The topic guide was designed to allow the discussion to be participant-led by avoiding fully formed questions, instead using prompts to stimulate the conversation. The topic guide explored themes such as:

- background information on the participant;
- how the participant's health condition or impairment affected their travel behaviours;
- each stage of the participant's most common journey across any form of travel; and,
- barriers to travel.

Interviews also explored other types of journeys, such as by private car, air and water, and concluded with final thoughts and suggestions for improvements. For more detail on the topic guide see the baseline technical report.

Interviewers were flexible about the length and format of the interview and were led by participants as to whether they required short breaks or needed the length of the interview reduced to aid participation. Interviewers were also sensitive to participants' health conditions or impairments and sought to mirror participants' language in describing their impairment or condition throughout the interview.

While the plan was to conduct majority of the interviews face-to-face, due to COVID-19 all interviews were completed by telephone or via video call. The interviews lasted about an hour on average.

With permission from participants, all interviews were digitally recorded on encrypted devices and were transcribed verbatim for detailed analysis and quality assurance.

4. Analysis

Interviews were transcribed then thematically categorised using Framework in NVivo, a qualitative data management approach developed by NatCen (Ritchie et al., 2013). A matrix was set up, with each column representing a key sub-theme and each row representing an individual case. For each case, data relating to each sub-theme was summarised within the relevant cell.

The categorisation of data produced for the ITS baseline report was structured around transport mode, key barriers and enablers and suggested improvements. As this didn't fully cover the scope of additional analysis, the matrix was expanded to capture information about disabled people's decision-making processes.

Analysis involved recategorising the data according to the revised matrix, before seeking to identify similarities, differences and thematic patterns. Throughout this process, we explored whether disabled people's choices and experiences could be classified according to characteristics such as disability type, demographics or by overall attitudes.

Endnotes

[a] Office for National Statistics (2021) Outcomes for disabled people in the UK.
[b] Office for National Statistics (2021) Disability pay gaps in the UK.
[c] Scope (2019) Disability Price Tag.
[d] Department for Transport (2019) Access to Transport and Life Opportunities.
[e] Respondents could select multiple disability types.
[f] Included people that had problems with dexterity, stamina or fatigue, those with mental health, social or behavioural issues, speech impairment or any other condition. During recruitment the quota for the Other category was increased from 8 to 12 to encompass the wide range of disabilities included.
[g] These were not exhaustive or mutually exclusive categories.
[h] Respondents could select both air and water travel.
[i] Monitoring of frequency involved logging whether each once per year/never transport mode was used: at least once a day/at least once per week/at least once per month/at least