

# **Building Confidence – Improving travel for people with mental impairments**

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## Executive Summary

The Equality Act was passed in 2010 by the UK parliament to reduce socio-economic inequalities and eliminate discrimination on various grounds including disability. The Act states that a person has a disability if he or she has a physical or mental impairment that has a substantial and long-term effect on the ability to carry out everyday activities including travelling.

The following mental skills are required to make a journey: the ability to remember information obtained previously, comprehension of information received from outside sources, the ability to take decisions based on this information, interpersonal communication skills, confidence in travelling alone, and the ability to behave in line with contemporary social norms. The mental skills required at each step of a journey can be identified. There are several types of mental impairment which can adversely affect these skills. Learning disabilities develop at about the time of birth and affect a person for their whole lifetime. Cognitive impairments usually develop later in life, some gradually, such as dementia, others suddenly, for example as a result of a brain injury. There are behavioural conditions such as autism and mental health conditions which include depression, anxiety and agoraphobia.

People with mental impairments make fewer journeys than the rest of the population. This is because some people with a mental impairment have difficulties going out at all, for example because of their lack of confidence to travel, concerns about the attitudes of other people, both staff and fellow passengers, and the cost of travel as many people with mental impairments have low incomes because they are unable to access suitable employment.

There are issues associated with travel by specific modes by people with mental impairments. For walking, as well as anxieties about tripping, bumping into other people and crossing the road, some people with mental impairments have difficulties navigating. Research suggests that being given directions using landmarks is the most effective way of providing guidance, and that having a mobile phone is useful for receiving reassurance and assistance when lost.

Bus offers the opportunity to travel further than walking and may be the only mode available for some people with mental impairments to make longer trips. Bus drivers are sometimes unhelpful, rude, unable to communicate well, and lacking in knowledge about bus routes and timetables; they occasionally take advantage of people with mental impairments; the behaviour of other passengers can cause difficulties by smoking, drug taking, playing loud music and bullying, and schoolchildren can be noisy and bang on the side of the bus; overcrowding can cause problems for some people. Some people with mental impairments with low incomes may find bus travel expensive because they have been assessed as ineligible for a concessionary bus pass; others may not realise that they are entitled to have one; some of those who do have a concessionary bus pass, may have difficulty understanding the rules. When a bus service is disrupted, the lack of an explanation may cause distress; people with mental impairments may lack the ability to generalise about what to do in a novel situation, such as a disrupted journey or a bus terminating short of the advertised destination; when bus routes are revised a person who has had travel training will need to learn about the new routes and this may interfere with knowledge about previously learned routes.

Services such as dial-a-ride can be very useful for people with mental impairments because they can offer a way for some people to make journeys that they may find difficult by conventional buses, but there can be constraints imposed by the timing of services such as finishing part way through the evening and the effects of not crossing local authority boundaries which can prevent some social trips. In some places people with mental impairments may not be eligible to use these services or only be allowed to travel with a carer.

For rail travel, cost is the most critical factor for people with mental impairments because of their low incomes. Anxiety and lack of confidence are also major deterrents. One group that has particular difficulties with rail travel is people with mental health conditions because, for some of them, their condition can fluctuate from day to day, which prevents them from committing to a journey in advance and so they cannot take advantage of some cheaper fares. Positive aspects of rail travel for some people with mental impairments are the amount of space offered and the availability of toilets on some trains which reduces one aspect of anxiety. However, aspects of the modern design of trains cause problems for some people with mental health conditions, for example, sealed windows in air-conditioned carriages and electronic doors which cannot be opened manually including toilet doors.

Taxis are a very suitable mode of travel for some people with mental impairments because they convey the traveller from door to door and, if another person makes the booking, gives the driver the location of the destination and makes the payment, require no interaction with any other person.

Cars offer the opportunity to travel door to door without needing to interact with strangers which may suit some people with mental impairments, but many of them are not allowed to have a driving licence, so they can only travel as passengers. In Britain, the DVLA must be informed about many mental impairments. Some people with conditions such as learning disabilities which are acquired about the time of birth, are never likely to be able to drive a car, but other conditions are acquired later in life, for example, dementia. In these cases, the person concerned may have driven for many years, but then suffer from loss of mental agility, judgement and memory, which means that they are no longer able to drive. However, because the condition is progressive, a critical issue is the point at which a person with dementia is no longer safe to drive. The evidence suggests that most people with dementia cease driving within three years of the first signs of the disease. A difficult question is how the decision is taken, both in terms of how the person concerned is made aware that there may be an issue, and who decides. Some people with mental impairments are able to drive but need a subsidy in order to purchase a car in the same way as some people with physical disabilities. In some cases, this will enable them to be employed rather than remaining at home in need of benefits to provide their incomes. The eligibility criteria are defined in terms of the ability to walk a certain distance. However, some people with the mental impairments would benefit from more flexible rules which mean that mental factors influencing the ability to walk are included in the criteria.

Interventions can help people with mental impairments travel more by enhancing the skills of the traveller or modifying the travelling environment to reduce the needs for such skills. Interventions to help preparation for travel include travel training and clear pre-travel

information, including inclusive travel guides. Improvements that can be made to the journey include making the local environment easier to understand, providing car parking near the destination and providing special transport services. Better support from people on the journey can be provided in various ways including staff training, travel assistance cards and Safe Place schemes. Appropriate information can be provided on the journey using audio-visual systems and mobile phone apps. Interventions can be packaged together through schemes such as personalised travel planning and dementia-friendly communities. These are discussed in the report in detail.

The conclusions of the report are:

- A number of skills are used in travel, including recalling and assimilating information, taking decisions based on that information, having the confidence to travel alone, being able to communicate with other people and behaving in line with contemporary social norms;
- There are a number of mental impairments including dementia, autism, and mental health conditions that affect a person's ability to travel because they adversely affect these travel skills;
- People with mental impairments travel less than other people despite the evidence about the positive aspects of travel for people with mental impairments;
- The major reasons for relatively low levels of public transport use by people with mental impairments are anxiety and lack of confidence caused by a number of factors including the behaviour and attitudes of staff and other travellers, difficulty navigating along the street and through stations, the lack of accessible information at the appropriate time and concerns about becoming lost and possible disruption to the journey; other reasons include the cost of travel because many people with mental impairments have low incomes and are not eligible for some travel facilities and concessions;
- Various interventions can be used to address these issues by:
  - Enhancing the travel skills of people with mental impairments;
  - Reducing the need for travel skills by simplifying travel and so reducing the need to make decisions;
  - Increasing the confidence of travellers by providing clear, accessible information at the appropriate time to assist decision making and reducing the risk of information being forgotten;
  - Improving the confidence of travellers by providing support from empathetic people during the journey;
  - Providing cheaper travel for people with mental impairments.
- The travel skills of people with mental impairments can be enhanced through travel training and providing experience using public transport;
- Journeys can be simplified by using coherent signage at critical decision points and simplification of the environment, by allowing use of special transport services such as dial-a-ride, and providing car parking near the destination for those who find it

difficult to walk long distances, those who cannot be left alone or those who may need to be escorted away from other people quickly;

- Clear information in appropriate formats can be provided both before travel and during the journey; the former includes inclusive travel guides and coherent travel planning information, both on-line and on paper, the latter can be through clear signage, AVI and mobile phone apps;
- The confidence to approach staff can be increased by better staff training and providing travel assistance cards;
- There are a number of schemes that have been set up to increase the self-confidence of people with mental impairments to travel alone such as Safe Place schemes, tracking of people with dementia and schemes offering experiences such as using railways and bus stations, but they rely on local initiatives and not available across the country; these schemes are relatively inexpensive, so there is a strong case for sharing information about the schemes, for example, through a single website containing information about a range of initiatives that can improve accessibility for people with mental impairments;
- Mobile phone apps have great potential to assist people with mental impairments when travelling, for example by providing route information including directions at junctions when walking and real time information about bus arrivals, and by allowing monitoring of the person's location by a carer or agency; however, examination of the literature suggests that people with mental impairments are not always involved in the design and evaluation of such apps;
- People with some mental impairments are not eligible for some travel concessions such as concessionary passes for bus travel, Disabled Persons Railcards and reduced price car leasing; changing the eligibility criteria could increase the mobility of some people with mental impairments;
- Some people with mental impairments are not aware that they may be eligible for some travel concessions, so publicity campaigns could be used to increase awareness;
- Personalised travel schemes based on the concept of analysing the travel needs of small groups of individuals in the context of the available budget offer the potential to meet the travel needs of people with mental impairments more effectively and save resources compared to more conventional approaches;
- Dementia-friendly communities offer people with dementia the opportunity to travel quite widely with confidence and have a well-defined path to implementation;
- People with degenerative conditions such as dementia have to give up driving, usually within three years of the diagnosis of the condition; because of the major implication of having to cease driving, how and when the decision is made can have a significant effect on their quality of life;
- There is evidence that the public have negative perceptions of people with mental impairments; these could be addressed through campaigns similar to those introduced to combat other forms of discrimination.

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## 1 Introduction

In 2010, the UK Parliament passed the Equality Act<sup>1</sup> in order to reduce socio-economic inequalities and to eliminate discrimination. It replaced a number of earlier pieces of legislation including the Disability Discrimination Act 1995. The Equality Act 2010 covers a number of personal characteristics including age, race, sex and disability. The legislation says that a person has a disability if he or she has a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.

It is important to understand the distinction between an impairment and a disability. According to the report 'Fulfilling Potential: Building a deeper understanding of disability in the UK today'<sup>2</sup>:

- An impairment is a difficulty with physical or mental functioning which limits day-to-day activities as a result.
- A disability is the dynamic interaction between an impairment and attitudinal and environmental barriers that hinders a person's full and effective participation in society on an equal basis with others.

This distinction is part of the social model of disability which recognises that disability is caused by the way society is organised, rather than by the impairment that a person has. This means that it is necessary to consider attitudinal and environmental barriers in trying to meet the needs of disabled people and to conform to the Equality Act 2010.

The Appendix to the Guidance to the Equality Act<sup>3</sup> gives some examples of substantial adverse effects on normal day-to-day activities which include difficulty using transport, difficulty going outdoors unaccompanied and persistent difficulty crossing a road safely. The Equality Act 2010 includes a duty on service providers to make 'adjustments' where a disabled person is at a substantial disadvantage in comparison with people who are not disabled by taking reasonable steps to avoid the disadvantage. When the adjustment involves the provision of information, it must be provided in an accessible format.

Much work has been done to reduce the barriers to travel<sup>4</sup>, but much of the emphasis has been on investment in engineering solutions, for example, ramps to enable people in wheelchairs to change level and access buildings and tactile paving to assist blind people in wayfinding on the street. While much remains to be done in relation to physical access, it can

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<sup>1</sup> H M Government, **Equality Act 2010** (2010), available from [http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga\\_20100015\\_en.pdf](http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf).

<sup>2</sup> Department for Work and Pensions, **Fulfilling Potential: Building a deeper understanding of disability in the UK today** (2013), available from <https://www.gov.uk/government/publications/fulfilling-potential-understanding-disability>.

<sup>3</sup> Office for Disability Issues, **Equality Act 2010: Guidance** (2011), available from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/85010/disability-definition.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/85010/disability-definition.pdf).

<sup>4</sup> Department for Transport, **Inclusive Mobility Guidelines** (2005), available from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/3695/inclusive-mobility.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/3695/inclusive-mobility.pdf).

be argued that much less has been done to address the needs of people with mental impairments. This may be because engineering solutions are less appropriate in these cases.

From the discussion above, it can be seen that there are legal as well as moral reasons to reduce the barriers to travel for people with mental impairments. There are also social and economic reasons for doing so, for example to increase community cohesion and to enhance the contribution that people with mental impairments make to the economy. The purpose of the report is to establish the existing evidence about the barriers that adversely affect accessibility for people with mental impairments such as dementia, learning disabilities and mental health conditions and identify suitable ways of overcoming the barriers. Whilst there is some evidence in the academic literature, most of it is in reports produced by various stakeholders, published or unpublished, on websites and within the knowledge of various experts. Papers in the academic literature were found by searching various data bases including TRIS and Google Scholar using combinations of key words representing accessibility and various types of cognitive impairments and then following up on relevant references from the papers that were found. The 'grey literature' was found by searching websites of relevant organisations such as the Alzheimer's Society and Mencap using terms such as 'travel' and 'car'. A list of experts was produced by sending emails to various organizations that represent people with mental impairments and transport providers, as well as the existing knowledge of the author. Experts were asked to suggest others with useful knowledge. These experts provided information through face-to-face and telephone interviews. They also sent information by email, including reports from their organizations. In addition, data were analysed from the National Rail Passenger Survey and the National Bus Passenger Survey, both organised by Transport Focus and the Life Opportunities Survey produced by the Office for Disability Issues.

In the next section, the nature of the mental skills used in travel are considered, followed by discussion about the range of mental impairments and how these may affect these skills. Evidence on the use of various modes of travel by people with these impairments is examined in the next section. Then a range of interventions are considered including some which enhance the mental skills of travellers and others which modify the travel environment in order to enable people with mental impairments to make the journeys that they wish to. In the final section conclusions are drawn.

## **2 The mental skills used in travel**

Various mental skills are used in making a journey even though, for much of time, the traveller is probably not aware that they using such skills. All journeys require some form of navigation (or wayfinding), following the chosen route to reach the desired destination. This means processing information which has either been recalled from memory or obtained during the

journey and then taking decisions based on it. A theoretical model of route direction production containing three elements has been suggested<sup>5</sup>:

- Activation of the spatial knowledge of the environment; this information will be stored by the user in their brain;
- Choice of the specific route through the environment which may be based on various criteria, including choice of mode, desired route characteristics (choice of mode, speed, scenery, etc.);
- Translation into a set of instructions.

Most journeys include an element of walking, for example from the origin to the bus stop, railway station or car. Many other journeys just involve walking. A key aspect of walking alone is the ability to find the way, that is, navigation or wayfinding. There has been some research into the ways people find their way when walking. Denis and colleagues carried out four linked studies in Venice<sup>6</sup>. The first one used 19 subjects aged 19-40 who knew Venice well to produce instructions about three walking routes in Venice. The selection criteria for the sample is not indicated. The second study involved 46 young adults aged 20-30, half familiar with Venice, half not, who were asked to produce reduced versions of the instructions from the first exercise. Those familiar with Venice were all students at the University of Venice, while those not familiar were students at other universities in northern Italy who declared that they were not familiar with Venice. In the third study, 10 young people aged 19-27, half familiar with Venice, half not, were asked to rate the 19 descriptions of the three routes. In the fourth study, 18 subjects who were unfamiliar with Venice used the various descriptions to follow the three routes and were followed by members of the team. They found that landmarks had an important role to play at the approach to critical nodes where an orientation problem was to be solved, but that only a small subset of the possible landmarks were used in the descriptions. They found that, when asked to produce a more concise version of the instructions, people who were familiar with the city and those who were not, produced very similar skeletal sets of instructions, suggesting that they were using metacognitive information about route directions that was independent of the level of familiarity with the environment.

Lovelace and colleagues carried out research with students to establish the best ways to provide good route directions<sup>7</sup>. They considered the issue of the best way to provide the instructions to follow a specific route. In the experiment, 31 students were required to find

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<sup>5</sup> Lovelace K L, Hegarty M, and Montello D R, Elements of good route directions in familiar and unfamiliar environments, in C Freksa and D M Mark (Eds), **Spatial Information Theory: Cognitive and computational foundations of geographic information science**, 1661 (1999), 65–82 (Springer, Berlin and Heidelberg), available from [http://link.springer.com/chapter/10.1007/3-540-48384-5\\_5](http://link.springer.com/chapter/10.1007/3-540-48384-5_5).

<sup>6</sup> Denis M, Pazzaglia F, Cornoldi C, and Bertolo L Spatial discourse and navigation: An analysis of route directions in the city of Venice, **Applied Cognitive Psychology**, 13(2) (1999), 145–174, available from [http://onlinelibrary.wiley.com/doi/10.1002/\(SICI\)1099-0720\(199904\)13:2%3C145::AID-ACP550%3E3.0.CO;2-4/pdf](http://onlinelibrary.wiley.com/doi/10.1002/(SICI)1099-0720(199904)13:2%3C145::AID-ACP550%3E3.0.CO;2-4/pdf).

<sup>7</sup> See note 5.

their way around unfamiliar parts of their university campus. They were guided along an unfamiliar route which took about eight minutes. At the end of the journey they were asked to write down directions to follow the route for a person who was not familiar with the campus. They were then taken on a second unfamiliar walk and at the end of it they were given twenty photographs, ten of them of landmarks passed on the walk, ten of them of similar landmarks elsewhere on the campus, and asked if they had seen the landmarks on their journey. Finally they were asked to retrace their way back to the beginning of the second journey. The researchers found that the ability to retrace a newly-learned route was correlated with the quality of the quality of the route directions given. They found that the students, when describing the route, gave less detailed information near the end of the journey, possibly because the final destination is in sight. The researchers concluded that landmarks are important in giving route directions, that people can manage quite complex instructions when they are given in writing, but that when given orally, the directions need to be concise. More generally, they concluded that individuals should be primed about decision points that were coming up, redundant information should be limited and route instructions should be given from the perspective of the navigator.

The research outlined above suggests that landmarks are useful in finding the way, and that many people have an innate way of finding their way based on experience that is independent of their level of familiarity with the local area. This implies a need to be able to remember and recall information, linked with an ability to interpret what can be seen around the traveller.

One of the commonest forms of travel by disabled people is the bus. There are a number of tasks involved in making a bus journey which Hunter-Zaworski and Hron have identified<sup>8</sup> including:

- The ability to evaluate what is needed to make the journey including route and fare information;
- Understanding the system, including learning routes, stops and transfer points, understanding the timetable and fare system;
- Accessing the correct vehicle which requires recognising it and processing information about the route number and destination;
- Entering the vehicle including paying the fare;
- Travelling on the vehicle;
- Leaving the vehicle including knowing where to alight and when the vehicle is approaching the stop;
- Leaving the stop or station.

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<sup>8</sup> Hunter-Zaworski K M and Hron M, **Improving Bus Accessibility Systems for Persons with Sensory and Cognitive Impairments**, Publication DOT-T-94-04 (1993), Federal Transit Administration, Washington, DC, available from <http://ntl.bts.gov/lib/6000/6400/6431/sci.html>.

Similarly, the Autistic Society Greater Manchester Area identified the following tasks undertaken in making a bus journey<sup>9</sup>:

- Getting to the bus stop;
- Reading bus timetables;
- Reading electronic displays;
- Talking to the driver, for example, asking for the correct fare;
- Knowing where to sit on the bus;
- Understanding issues of personal safety and security;
- Knowing how to cope when a bus is late;
- Dealing with changes to the route or the operating company (for example, the bus might be a different colour).

There may be a difference in the mental skills required between making a familiar journey and an unfamiliar one. Carmien and colleagues<sup>10</sup> argue that navigating public transport involves complex and difficult executive function cognitive skills and that regular travellers use personally meaningful artefacts such as landmarks and local experience for navigating while travelling whereas infrequent travellers have to rely on abstract navigation artefacts such as maps and timetables and general knowledge about how systems function.

Driving a car requires a slightly different range of skills because the driver is in direct control of the vehicle and may need to perceive the need for sudden action, absorb the relevant information, and act upon it. Vichitvanichphong and colleagues undertook a literature review<sup>11</sup> which identified the following cognitive abilities associated with driving:

- Self-regulation of driving: the ability to perceive and decide whether oneself is able to drive;
- Visual memory: the ability to store and retrieve previously experienced visual sensations and perceptions;
- Working memory: the ability to hold relevant information in mind and ignore irrelevant information
- Visuospatial perception: the ability to process and interpret visual information about where objects are in space
- Semantic fluency: the ability to distinguish between different words and symbols;
- Orientation: the ability to relate physical position and direction;

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<sup>9</sup> Autistic Society Greater Manchester Area, **Travel Training: For travel trainers of people with autistic spectrum disorders** (2006), available from [http://www.tfgm.com/accessible\\_transport/Documents/ASGMA\\_Training\\_Guide.pdf](http://www.tfgm.com/accessible_transport/Documents/ASGMA_Training_Guide.pdf).

<sup>10</sup> Carmien S, Dawe M, Fischer G, Gorman A, Kintsch A, and Sullivan J F, Jr, Socio-Technical Environments supporting people with cognitive disabilities using public transportation, **Transactions on Computer-Human Interaction**, **12** (2005), 233–262, available from <http://l3d.cs.colorado.edu/clever/projects/maps/papers/TOCHI-submitted-2-26-04.pdf>.

<sup>11</sup> Vichitvanichphong S, Talaei-Khoei A, Kerr D and Hossein G A, What does happen to our driving when we get older? **Transport Reviews**, **35** (2015), 56-81, doi:10.1080/01441647.2014.997819, available from <http://www.tandfonline.com/doi/abs/10.1080/01441647.2014.997819#.VMoEzNhLdhd>.

- Ability to process information;
- Mental flexibility: the ability to cope with various circumstances in different ways, particularly responding effectively to new, complex and problematic situations;
- Executive abilities: the ability to carry out actions having processed information;
- Attention and concentration: the ability to focus on the current action;
- Ability to react.

The various tasks described above are largely about the ability to obtain information, process it and then take decisions, often associated with navigation, but may also include decisions about the type of ticket to obtain, where to sit on a bus or train and how to continue the journey when it is disrupted by exogenous circumstances or the traveller feels unwell. On many journeys, particularly by bus, rail or taxi, it is necessary to interact with members of staff. Even though it is often possible to buy public transport tickets from machines or use a pass, there are likely to be occasions during any journey when it is necessary to communicate with staff, for example to obtain information, when random checks are performed for revenue protection purposes and when the service is disrupted. This is all underpinned by having the self-confidence to travel; that is, not just having the ability to travel, but being sufficiently aware of one's own abilities to undertake and complete the journey successfully including being able to cope with unexpected difficulties. Travel by bus, rail and walking involve travel in public space and therefore being visible to other people. Whilst there may be no explicit interaction with others, behaviour outside the norms expected by society may cause distress to others or cause them to react in a way that embarrasses the traveller, for example by staring or making insensitive comments. As individuals progress through the life-cycle their pattern of behaviour changes, and the perceptions and expectations of them by others change. A child may behave in a particular way which is regarded as acceptable, whereas similar behaviour by an adult, for example talking more loudly than the norm or running around, may be regarded as unacceptable.

Summarising the information above, six mental skills used in travelling can be identified:

- **The ability to remember:** travelling requires the recall of information obtained previously, for example the route to the bus stop, which bus to catch and the final destination;
- **Comprehension:** the ability to understand information from explicit sources during the course of the journey such as direction signs, electronic screens and people, by interpreting the landscape, such as landmarks, and intuitively, such as having a sense of direction;
- **Decision making:** the ability to process information and to make decisions based on it, for example, whether to turn left or right, deciding when to indicate to the driver to stop the bus and deciding how much time to allow for interchange;
- **Interpersonal communication skills:** the ability to understand others and convey information to them, for example, buying a ticket, asking for assistance and understanding requests from other passengers;

- **Having the confidence to travel alone:** having the self-confidence to obtain enough information and process it to reach the destination efficiently and knowing how to cope if things go wrong;
- **The ability to behave appropriately** in line with the contemporary norms expected by society for a person of the age of the traveller.

These six mental skills will be used in this report. The skills required to make a specific journey can be identified by breaking it down into the various stages and then considering the skills required for each of them.

Based on the evidence discussed above and observation, a walking journey, typically, involves the following stages:

- Planning the journey: reading a map on paper or online, or remembering from previous experience; it may not be necessary or even desirable to plan an exact route on occasion;
- Remembering the chosen route, or, at least, the final destination;
- Understanding about personal safety and security;
- Understanding information from signposts and other visual clues;
- Making wayfinding decisions on the route at junctions and other decision points;
- Being able to cross the road safely;
- Coping when lost;
- Interacting with other people, e.g. for information or in case of emergency.

The mental skills used at these stages in a walking journey are shown in Table 1.

Table 1 The mental skills used to make a walking journey

<b>Mental skill</b>	<b>Stages in making a walking journey</b>	
Ability to remember	Planning the journey Remembering the journey being made	Wayfinding Coping when lost
Comprehension	Planning the journey Understanding about personal safety and security Coping when lost	Understanding information from signposts and other visual clues Interacting with other people
Decision making	Planning the journey Wayfinding	Crossing the road Coping when lost
Interpersonal communication	Interacting with other people	
Confidence in travelling alone	Wayfinding Crossing the road	Coping when lost Interacting with other people
Ability to behave appropriately	Interacting with other people	

A bus journey involving walking to the bus stop, travelling on one bus and walking to the destination, typically, involves the following stages:

- Planning the journey: reading and understanding a timetable and, if necessary, a bus map, on paper or online, or remembering from previous experience;
- Remembering the chosen route;
- Understanding about personal safety and security;
- Wayfinding to the bus stop;
- Understanding visual clues such as which buses stops at a particular stop and the numbers on buses;
- Deciding on the correct bus stop;
- Deciding on the correct bus;
- Boarding the bus;
- Purchasing a ticket from the driver, a sales kiosk or machine, including requesting the correct ticket and understanding the financial transaction;
- Finding a seat;
- Interacting with fellow passengers;
- Understanding audio-visual information (AVI) during the journey;
- Recognising where to alight;
- Indicating to the driver to stop;
- Alighting from the vehicle;
- Wayfinding to the final destination;
- Coping with a disrupted journey, for example when a bus is late, stops short of the destination or the service is disrupted.

The stages in a bus journey when the mental skills are required are indicated in Table 2.

A rail journey involve requires a similar set of skills to a bus journey:

- Planning the journey: reading a timetable, and possibly a map, on paper or online, or remembering from previous experience;
- Remembering the chosen route;
- Travelling to the railway station by walking, bus or car;
- Purchasing a ticket from the ticket office or machine, including requesting the correct ticket and understanding the financial transaction;
- Finding the correct station platform;
- Deciding on the correct train;
- Knowing how to get on the train;
- Finding a seat;
- Interacting with fellow passengers;
- Talking to staff, for example, revenue protection staff;
- Understanding AVI during the journey;
- Knowing how to recognise where to get off;
- Knowing how to get off the train;
- Knowing how to reach the final destination;

- Understanding issues of personal safety and security;
- Knowing how to cope when a train is late or the service is disrupted.

The stages in a rail journey when the mental skills are required are indicated in Table 3.

Table 2 The mental skills used to make a journey using one bus

<b>Mental skill</b>	<b>Stages in making a bus journey</b>	
Ability to remember	Planning the journey Remembering the route Wayfinding to the bus stop	Wayfinding to the final destination Coping with a disrupted journey
Comprehension	Planning the journey Understanding about personal safety and security Understanding visual clues	Purchasing a ticket Understanding AVI Coping with a disrupted journey
Decision making	Planning the journey Wayfinding to the bus stop Deciding on the correct bus stop Deciding on the correct bus Purchasing a ticket	Choosing a seat Deciding when to alight Wayfinding to the final destination Coping with a disrupted journey
Interpersonal communication	Purchasing a ticket Interacting with fellow passengers	Coping with a disrupted journey
Confidence in travelling alone	Wayfinding to the bus stop Indicating to the driver to stop Boarding the bus Purchasing a ticket Choosing a seat	Interacting with fellow passengers Alighting from the bus Wayfinding to the final destination Coping with a disrupted journey
Ability to behave appropriately	Purchasing a ticket	Interacting with fellow passengers

Interchange between two buses, two trains or a bus and a train involves a subset of the stages indicated in Tables 2 and 3, including finding the correct bus stop or railway platform, deciding on the correct bus or train, finding a seat and recognising where to alight. In addition it may require judgement both at the planning stage and during the journey about the amount of time to allow between the first bus or train and the second.

One form of public transport which offers relatively simple journeys is taxi. The traveller only needs to know the destination, because all navigation is done by the driver and so the traveller needs to make no decisions during the course of the journey having informed the driver, either directly when entering the taxi or indirectly when booking it in advance. The following tasks are involved in making a taxi journey:

- Planning the journey: deciding on the destination and timing;
- Understanding issues of personal safety and security;
- Ordering the taxi either during the course of the journey or in advance by telephone or over the internet;
- Interacting with the driver at the beginning of the journey;

- Paying for the journey.

It should be noted that it is possible for a person other than the traveller to carry out the tasks of planning the journey, ordering the taxi, interacting with the driver and paying for the journey. This would mean that the traveller would not need to use any mental skills, but an understanding of issues of personal safety and security would be advantageous. If the person making the journey carries out the tasks, the mental skills used are as indicated in Table 4.

Table 3 The mental skills used to make a journey using one train

<b>Mental skill</b>	<b>Stages in making a rail journey</b>	
Ability to remember	Planning the journey Remembering the route Wayfinding to the station	Wayfinding to the final destination Coping with a disrupted journey
Comprehension	Planning the journey Understanding issues of personal safety and security Understanding visual clues	Purchasing a ticket Understanding AVI Coping with a disrupted journey
Decision making	Planning the journey Wayfinding to the station Purchasing a ticket Deciding on the correct platform Deciding on the correct train	Choosing a seat Deciding when to alight Wayfinding to the final destination Coping with a disrupted journey
Interpersonal communication	Purchasing a ticket Interacting with fellow passengers	Interacting with on-board staff Coping with a disrupted journey
Confidence in travelling alone	Wayfinding to the station Purchasing a ticket Boarding the train Choosing a seat Interacting with fellow passengers	Interacting with on-board staff Alighting from the train Wayfinding to the final destination Coping with a disrupted journey
Ability to behave appropriately	Purchasing a ticket Interacting with fellow passengers	Interacting with on-board staff

Table 4 The mental skills used to make a journey using a taxi

<b>Mental skill</b>	<b>Stages in making a taxi journey</b>	
Ability to remember	Planning the journey	
Comprehension	Planning the journey	Understanding issues of personal safety and security
Decision making	Planning the journey	Paying for the journey
Interpersonal communication	Ordering the taxi Interacting with the driver	Paying for the journey
Confidence in travelling alone	Interacting with the driver	
Ability to behave appropriately	Interacting with the driver	

The stages involved in making a car journey as a driver are, typically, as follows:

- Planning the journey: reading a map on paper or online, or remembering from previous experience; it is then necessary to remember the chosen route unless satellite navigation is being used;
- Controlling the car (changing gears, steering etc.);
- Understanding information from signposts and other visual clues;
- Making navigation decisions such as which route to take at junctions unless satellite navigation is being used;
- Making route changes because of congestion etc.;
- Communicating with others if assistance is required.

The mental skills involved in driving in the list above were based on the literature review by Vichitvanichphong and colleagues<sup>12</sup>. These can be simplified to the six mental skills discussed above, and then associated with the tasks involved in driving, as shown in Table 5.

Travelling as a car passenger does not require any mental skills, but they can be used for tasks such as reading maps, advising on routes to take and interpersonal communication.

In this section, the mental skills used in making a journey by various modes have been considered. As discussed in Section 1, an impairment is a difficulty with physical or mental functioning which limits day-to-day activities including making a journey. This report is focusing on mental impairments which are discussed in the next section. Then they will be considered in terms of the effect that they may have on the mental skills used in making a journey.

### **3 Mental impairments**

The Guidance to the Equality Act 2010<sup>13</sup> explains that a disability can arise from a variety of impairments including those which are progressive such as dementia, developmental such as autistic spectrum disorders (ASD), mental illnesses such as depression and schizophrenia, and mental health conditions with symptoms such as anxiety, panic attacks and phobias as well as a number of physical and sensory impairments. It also explains that, for the purposes of the Act, whether or not a person is disabled is generally determined by reference to the effect that his or her impairment has on the ability to carry out normal day-to-day activities. The Guidance to the Act also explains that a long-term effect is one that has lasted at least 12 months, is likely to last at least 12 months or the rest of the person's life. In the Appendix to the Guidance, the examples of substantial adverse affecting normal day-to-day activities include difficulty using transport because of a mental impairment or learning disability, difficulty going outdoors unaccompanied, for example because a person has a phobia or a learning disability, persistent difficulty crossing a road safely because of a failure to understand and manage the risk, and having behaviour which challenges people around the

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<sup>12</sup> See note 11.

<sup>13</sup> See note 3.

person, making it difficult for the person to be accepted in public places. These examples imply that a person with a mental impairment may have more limited mental skills of the type used in travelling such as those discussed in Section 2 of this report than many other people. Some people with mental impairments may also have physical impairments.

Table 5 The mental skills used to make a journey as a car driver

<b>Mental skill</b>	<b>Stages in making a journey as a car driver</b>	
Ability to remember	Planning the journey Remembering the route Controlling the car	Making route changes because of congestion etc.
Comprehension	Planning the journey Understanding information from signposts and other visual clues	Controlling the car Making route changes because of congestion etc.
Decision making	Planning the journey Making navigation decisions Controlling the car	Making route changes because of congestion etc.
Interpersonal communication	Communicating with others if assistance is required	
Confidence in travelling alone	Making navigation decisions Controlling the car Making route changes because of congestion etc.	Communicating with others if assistance is required
Ability to behave appropriately	Communicating with others if assistance is required	

In the UK, the Office for National Statistics has defined a set of impairments that are intended to cover the range of impairments that people may have<sup>14</sup>. The suggested initial question asked in surveys is 'Do you have any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more?' The categories are:

1. Vision (for example blindness or partial sight)
2. Hearing (for example deafness or partial hearing)
3. Mobility (for example walking short distances or climbing stairs)
4. Dexterity (for example lifting and carrying objects, using a keyboard)
5. Learning or understanding or concentrating
6. Memory
7. Mental health
8. Stamina or breathing or fatigue

<sup>14</sup> Office for National Statistics, **Long-lasting Health Conditions and Illnesses; Impairments and Disability, Harmonised Concepts and Questions for Social Data Sources: Primary Principles** (2015), available from <http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKEwiowJiNvlbNAhVslcAKHa-fC7oQFgggtMAA&url=http%3A%2F%2Fwww.ons.gov.uk%2Fons%2Fguide-method%2Fharmonisation%2Fprimary-set-of-harmonised-concepts-and-questions%2Flong-lasting-health-conditions-and-illnesses--impairments-and-disability.pdf&usq=AFQjCNEZGoLAltBD2h1knLzKhXsg07wGg>.

9. Socially or behaviourally (for example associated with autism, attention deficit disorder or Asperger's syndrome)
10. Other.

A physical or mental health condition or illness will not necessarily have an adverse impact on the ability to make a journey, and so, in surveys, a further question can be asked about whether this is the case. These categories are used in surveys such as the National Rail Passenger Survey<sup>15</sup>. Of the ten categories, 'Learning or understanding or concentrating', 'Memory', 'Mental health' and 'Socially or behaviourally' are mental impairments. Whilst these are useful categories, much of the evidence about the impacts of mental impairments on travel uses more specific conditions, so it is necessary to understand which impairments are included within these four categories.

Conditions that can affect learning or understanding or concentrating include:

- **Cerebral palsy:** this is the general term for a number of neurological conditions that affect movement and co-ordination<sup>16</sup>. One in four children with cerebral palsy have behaviour issues and some have learning disabilities<sup>17</sup>. It can make abstract ideas like letters and numbers trickier and hinder judgements about where steps and spaces start and finish. People can be more emotional and panicky than other people. When the brain is damaged it can affect movement, learning and speaking. Cerebral palsy can make it harder for sensory information, like light or sound, to get to the brain. It is estimated that 1 in 400 children born alive in the UK has cerebral palsy<sup>18</sup>.
- **Dementia including Alzheimer's disease:** Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities<sup>19</sup>. This includes problems with memory loss, thinking speed, mental agility, understanding and judgement. People with dementia may have problems controlling their emotions and find social situations challenging. As dementia affects a person's mental abilities, they may find planning and organising difficult. Dementia affects 5% of people over the age of 65 and 20% of those over 80<sup>20</sup>. There were 835,000 people with dementia in 2014 including 40,000 aged 65 and under<sup>21</sup>. It is forecast that there will be over 1 million by 2021 and 2 million by 2051.

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<sup>15</sup> Transport Focus, **National Rail Passenger Survey, 2016**, available from <http://www.transportfocus.org.uk/research-publications/research/national-passenger-survey-introduction/>.

<sup>16</sup> NHS Choices, Health A-Z - Conditions and treatments, **Cerebral Palsy**, available from <http://www.nhs.uk/conditions/Cerebral-palsy/Pages/Introduction.aspx>.

<sup>17</sup> SCOPE, **Cerebral Palsy**, available from <http://www.scope.org.uk/support/families/diagnosis/cerebral-palsy>.

<sup>18</sup> See note 16.

<sup>19</sup> NHS Choices, Health A-Z - Conditions and treatments, **About Dementia**, available from <http://www.nhs.uk/Conditions/dementia-guide/Pages/about-dementia.aspx>.

<sup>20</sup> Mental Health Foundation, **Mental health and later life**, available from <https://www.mentalhealth.org.uk/blog/mental-health-and-later-life>.

<sup>21</sup> Alzheimer's Society, **Dementia 2014: Opportunity for change**, available from [http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=2317](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2317).

- **Down's syndrome**, also known as Down syndrome, is a genetic condition that typically causes some level of learning disability and characteristic physical features<sup>22</sup>. Around 775 babies are born with the condition each year in England and Wales. Children with the condition may be slower to learn skills such as standing, walking and talking. Around 1 in every 10 children also experience additional difficulties such as autism spectrum disorder (ASD) or attention deficit hyperactivity disorder (ADHD).
- **Learning disability and learning difficulty**: There is some confusion in the literature between a 'learning disability' and a 'learning difficulty'. According to Mindroom<sup>23</sup> there is no single interpretation or consensual definition of the two terms but adopts the convention that 'difficulty' implies an obstacle while a 'disability' is something that incapacitates. Hence, a learning difficulty is any learning or emotional problem that affects a person's ability to learn, get along with others and follow convention while a learning disability is a significant, lifelong condition that starts before adulthood, affects development and leads to help being required to understand information, learn skills and cope independently. The NHS definition of a learning disability implies an IQ below 70. A learning disability is a reduced intellectual ability and difficulty with everyday activities, for example household tasks, socialising or managing money which affects someone for their whole life<sup>24</sup>. Around 1.5m people in the UK have a learning disability and up to 350,000 people have severe learning disabilities; this figure is increasing<sup>25</sup>. Out of every 100 people with a learning disability, around 22 of them also have epilepsy<sup>26</sup>. Dyslexia is a form of learning difficulty<sup>27</sup>. Unlike a learning disability, intelligence is not affected. It is a neuro-developmental condition characterised by specific problems in learning to read and write but these are not due to intellectual impairment. Some possible features of dyslexia include problems in distinguishing left and right, poor sense of direction, poor working memory, difficulties with time and tense, and visual and auditory perceptual difficulties. It is estimated that up to 1 in every 10 to 20 people in the UK has a certain degree of dyslexia.
- **Mild cognitive impairment (MCI)** is a term used to describe a condition involving problems with cognitive function, that is, mental abilities such as thinking, knowing and remembering<sup>28</sup>. People with MCI often have difficulties with day-to-day memory,

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<sup>22</sup> NHS Choices, Health A-Z - Conditions and treatments, **Down's syndrome**, available from <http://www.nhs.uk/conditions/Downs-syndrome/Pages/Introduction.aspx>.

<sup>23</sup> Mindroom: All kinds of minds, **What are learning difficulties?** available from [http://www.mindroom.org/index.php/learning\\_difficulties/what\\_are\\_learning\\_difficulties/](http://www.mindroom.org/index.php/learning_difficulties/what_are_learning_difficulties/).

<sup>24</sup> Mencap, **What is a learning disability?** Available from <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>.

<sup>25</sup> NHS Choices, Health A-Z - Conditions and treatments, **What is a learning disability?** available from <http://www.nhs.uk/Livewell/Childrenwithalearningdisability/Pages/Whatislearningdisability.aspx>.

<sup>26</sup> Epilepsy Action, **Carers of people with epilepsy and a learning disability**, available from <https://www.epilepsy.org.uk/info/learning-disabilities>.

<sup>27</sup> NHS Choices, Health A-Z - Conditions and treatments, **Dyslexia**, available from <http://www.nhs.uk/conditions/Dyslexia/Pages/Introduction.aspx>.

<sup>28</sup> Alzheimer's Society, **Mild cognitive impairment factsheet** (2015), available from [http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1773](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1773).

but such problems are not bad enough to be defined as dementia. A person with MCI has subtle problems with one or more of the following: day-to-day memory, planning, language, attention or visuospatial skills which give a person the ability to interpret objects and shapes. People who have MCI are at an increased risk of going on to develop dementia: research has shown that typically 10-15 per cent of people with MCI go to develop dementia each year.

- **Traumatic brain injury** is an injury to the brain caused by a head injury. The cognitive effects of a brain injury affect the way a person thinks, learns and remembers<sup>29</sup>. Different mental abilities are located in different parts of the brain, so a head injury can damage some or all skills such as speed of thought, memory, understanding, concentration, solving problems and using language. Communication problems after brain injury are very common. There were 348,934 UK admissions to hospital with acquired brain injury in 2013-14<sup>30</sup>. Acquired brain injury covers all situations in which brain injury has occurred since birth, and includes tumour, stroke, brain haemorrhage and encephalitis as well as traumatic brain injury.

From the descriptions of the various conditions that affect learning or understanding or concentrating, it can be seen that they may affect some of the mental skills used in travelling. These are indicated in Table 6. It should be stressed that the mental skill indicated will not be affected for everybody with a particular condition. It will depend on a number of factors, including the severity of the impairment. Nor does the absence of a link necessarily mean that they will not be an effect in some cases.

Table 6 Mental skills used in making a journey that may be affected by an impairment that affects learning or understanding or concentrating

	Ability to remember	Comprehension	Decision making	Interpersonal communication	Confidence in travelling alone	Ability to behave appropriately
Cerebral palsy		•	•	•	•	
Dementia	•	•	•	•	•	•
Down's syndrome		•	•	•	•	•
Learning difficulty	•	•	•			
Learning disability	•	•	•	•	•	•
Mild cognitive impairment	•	•	•			
Traumatic brain injury	•	•	•	•	•	•

<sup>29</sup> Headway, **Traumatic brain injury**, available from <https://www.headway.org.uk/about-brain-injury/individuals/types-of-brain-injury/traumatic-brain-injury/>.

<sup>30</sup> Headway, **Statistics**, available from <https://www.headway.org.uk/about-brain-injury/further-information/statistics/>.

Conditions that come under the heading of 'Socially or behaviourally' include:

- **Asperger's syndrome (or Asperger syndrome)** is an autistic spectrum disorder, often referred to as high functioning autism. A key feature of the condition is the lack of intuitive ability to adapt socially and fit in with others<sup>31</sup>. Language may be used in a stilted and stereotyped manner. People with Asperger's syndrome have no general cognitive delay, meaning their overall IQ is in the normal range or above. People with Asperger's syndrome do not usually have learning disabilities but may have learning difficulties, e.g. dyslexia.
- **Attention deficit hyperactivity disorder (ADHD)** is a group of behavioural symptoms that include inattentiveness, hyperactivity and impulsiveness<sup>32</sup>. Common symptoms of ADHD include a short attention span, being easily distracted, constant fidgeting, appearing forgetful, having difficulty organising tasks, and little or no sense of danger. ADHD is the most common behavioural disorder in the UK. Estimates suggest it affects around 2-5% of school-aged children and young people.
- **Autistic Spectrum Disorders (ASD):** Autism is a neurodevelopmental disorder that appears early in life, generally before the age of three<sup>33</sup>. Children with autism may have problems with relating to others, difficulties with communication, and limited imagination. Autistic traits persist into adulthood, but vary in severity. Autistic Spectrum Disorders are characterised by difficulties in three main areas: socialisation, communication and imagination. About 1.1% of the population (about 695,000 people) in the UK have autism. Between 44% and 52% of people with autism may also have a learning disability<sup>34</sup>. Only 16% of adults with autism are in full-time paid employment. 61% of those out of work and 79% of those on Incapacity Benefit say they want to work<sup>35</sup>.
- **Tourette's syndrome** is a complex neuro-developmental condition that is not emotional in its origin<sup>36</sup>. It is a condition in which the person loses control over the movements and sounds they make. These involuntary movements or sounds (tics) may come and go and vary in severity. Tourette syndrome is commonly associated with conditions such as Obsessive Compulsive Disorder, ADHD and motor skills and

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<sup>31</sup> Mindroom: all kinds of minds, **Autistic Spectrum Disorders (ASD)**, available from [http://www.mindroom.org/index.php/learning\\_difficulties/autistic\\_spectrum\\_disorders/](http://www.mindroom.org/index.php/learning_difficulties/autistic_spectrum_disorders/).

<sup>32</sup> NHS Choices, Health A-Z - Conditions and treatments, **Attention deficit hyperactivity disorder (ADHD)**, available from <http://www.nhs.uk/conditions/Attention-deficit-hyperactivity-disorder/Pages/Introduction.aspx>.

<sup>33</sup> See note 31.

<sup>34</sup> National Autistic Society, **Autism facts and history**, available from <http://www.autism.org.uk/about/what-is/myths-facts-stats.aspx>.

<sup>35</sup> National Autistic Society, **The Autism Employment Gap: Too Much Information in the Workplace** (2016), available from <http://www.autism.org.uk/~media/nas/get-involved/tmi/nas%20tmi%20employment%20report%2024pp%20web.ashx?la=en-gb>.

<sup>36</sup> Mindroom: All kinds of minds, **Tourette syndrome**, available from [http://www.mindroom.org/index.php/learning\\_difficulties/tourette\\_syndrome/](http://www.mindroom.org/index.php/learning_difficulties/tourette_syndrome/).

co-ordination difficulties. Tourette's syndrome affects around one in every 100 people<sup>37</sup>.

These conditions may affect the mental skills used to make a journey, as shown in Table 7.

Table 7 Mental skills used in making a journey that may be affected by an impairment that come under the heading of 'Socially or behaviourally'

	Ability to remember	Compre- hension	Decision making	Interpersonal communi- cation	Confidence in travelling alone	Ability to behave appropriately
Asperger's syndrome						•
ADHD	•	•	•	•		•
Autistic Spectrum Disorders			•	•		•
Tourette's syndrome	•					•

Mental health conditions include:

- **Agoraphobia** is a fear of being in situations where escape might be difficult, or help would not be available if things go wrong<sup>38</sup>. Symptoms of agoraphobia relating to behaviour include not being able to leave the house for long periods of time and avoiding situations that could lead to panic attacks, such as crowded places, public transport and queues. The onset of agoraphobia is usually between the ages of 18 and 35 and it affects between 1.5% and 3.5% of the general population<sup>39</sup>.
- **Anxiety** is a feeling of unease such as worry or fear that can be mild or severe<sup>40</sup>. Anxiety is the main symptom of several conditions, including panic disorder, phobias, post-traumatic stress disorder and social anxiety disorder. It can have a psychological impact which can include lack of concentration and loss of self-confidence. Generalised anxiety disorder is a common condition estimated to affect about 1 in every 25 people in the UK. Slightly more women are affected than men, and the condition is more common in people between the ages of 35 and 55 than other age groups. Anxiety does not affect insight or cognition<sup>41</sup>. Post-traumatic stress disorder

<sup>37</sup> NHS Choices, Health A-Z - Conditions and treatments, **Tourette's syndrome**, available from <http://www.nhs.uk/conditions/Tourette-syndrome/Pages/Introduction.aspx>.

<sup>38</sup> NHS Choices, Health A-Z - Conditions and treatments, **Agoraphobia**, available from <http://www.nhs.uk/conditions/Agoraphobia/Pages/Introduction.aspx>.

<sup>39</sup> Anxiety Care UK, **Agoraphobia**, available from <http://www.anxietycare.org.uk/docs/agoraphobia.asp>.

<sup>40</sup> NHS Choices, Health A-Z - Conditions and treatments, **Generalised anxiety disorder in adults**, available from <http://www.nhs.uk/conditions/anxiety/Pages/Introduction.aspx>.

<sup>41</sup> McManus Sally, Meltzer Howard, Brugha Traolach, Bebbington Paul and Jenkins Rachel, **Adult Psychiatric Morbidity in England, 2007**, The NHS Information Centre for Health and Social Care (2009), available from <http://www.hscic.gov.uk/catalogue/PUB02931/adul-psyc-morb-res-hou-sur-eng-2007-rep.pdf>.

(PTSD) is an anxiety disorder caused by very stressful, frightening or distressing events<sup>42</sup>. It can affect 3 in 100 people in a year<sup>43</sup>.

- **Bipolar disorder**, formerly known as manic depression, is a condition that affects moods, which can swing from one extreme to another<sup>44</sup>. A person with bipolar disorder will have periods or episodes of depression, where they feel very low and lethargic, and mania, where they feel very high and overactive. 1% to 2% of the population experience a lifetime prevalence of bipolar and recent research suggests as many as 5% of the population are on the bipolar spectrum<sup>45</sup>.
- **Depression** has psychological symptoms including finding it difficult to make decisions and loss of self-confidence and self-esteem<sup>46</sup>. Between 8 and 12% of the population experience depression in any year. Depression affects 1 in 5 older people living in the community and 2 in 5 living in care homes. It does not affect insight or cognition<sup>47</sup>.
- **Obsessive compulsive disorder (OCD)** is a mental health condition where a person has obsessive thoughts and compulsive behaviours<sup>48</sup>. It is estimated around 12 in every 1,000 people in the UK are affected by the condition<sup>49</sup>. This means that there are around 750,000 people living with OCD at any one time, with 50% of these cases falling into the severe category and less than a quarter being classed as mild.
- **Psychosis** is a mental health problem that causes people to perceive or interpret things differently from those around them<sup>50</sup>. This might involve hallucinations or delusions. It is often triggered by other conditions such as schizophrenia, bipolar disorder and severe depression.
- **Schizo-affective disorder**: A person may be given a diagnosis of schizo-affective disorder if they have episodes of mental ill-health when they experience psychotic symptoms, similar to schizophrenia, and the mood symptoms of bipolar disorder and have both psychotic and mood symptoms at the same time or within two weeks of each other<sup>51</sup>.

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<sup>42</sup> NHS Choices, Health A-Z - Conditions and treatments, **Post-traumatic stress disorder (PTSD)**, available from <http://www.nhs.uk/conditions/Post-traumatic-stress-disorder/Pages/Introduction.aspx>.

<sup>43</sup> Mind, **Mental health facts and statistics**, available from <http://www.mind.org.uk/information-support/types-of-mental-health-problems/statistics-and-facts-about-mental-health/how-common-are-mental-health-problems/#one>.

<sup>44</sup> NHS Choices, Health A-Z - Conditions and treatments, **Bipolar disorder**, available from <http://www.nhs.uk/conditions/Bipolar-disorder/Pages/Introduction.aspx>.

<sup>45</sup> Bipolar UK, **Bipolar – the facts**, available from <https://www.bipolaruk.org/Pages/FAQs/Category/what-is-bipolar>.

<sup>46</sup> Mental Health Foundation, **Depression**, available from <https://www.mentalhealth.org.uk/a-to-z/d/depression>.

<sup>47</sup> See note 41.

<sup>48</sup> NHS Choices, Health A-Z - Conditions and treatments, **Obsessive compulsive disorder (OCD)**, available from <http://www.nhs.uk/conditions/Obsessive-compulsive-disorder/Pages/Introduction.aspx>.

<sup>49</sup> OCDUK, **Understanding Obsessive-Compulsive Disorder (OCD)**, available from <http://www.ocduk.org/ocd>.

<sup>50</sup> NHS Choices, Health A-Z - Conditions and treatments, **Psychosis**, available from <http://www.nhs.uk/conditions/Psychosis/Pages/Introduction.aspx>.

<sup>51</sup> Mind, **Schizoaffective disorder**, available from <http://www.mind.org.uk/information-support/types-of-mental-health-problems/schizoaffective-disorder/#.WBoq-kawS9Y>.

- **Schizophrenia** is a long-term mental health condition that causes a range of different psychological symptoms, including muddled thoughts based on hallucinations or delusions and changes in behaviour<sup>52</sup>. It affects about 1 in every 100 people and usually starts during early adulthood<sup>53</sup>. During an episode of schizophrenia, a person's understanding and interpretation of the outside world is disrupted: they may hold irrational or unfounded beliefs and appear to act strangely because they are responding to delusions and hallucinations<sup>54</sup>.

In England, 26% of all adults report having been diagnosed with at least one mental illness, while a further 18% say that they have experienced a mental illness without being diagnosed<sup>55</sup>. More women than men report having been diagnosed with a mental illness. The prevalence is highest between the ages of 27 and 74, peaking in the 55-64 age group.

These mental health conditions may affect some of the skills used in making a journey, as shown in Table 8.

Table 8 Mental skills used in making a journey that may be affected by a mental health condition

	Ability to remember	Comprehension	Decision making	Interpersonal communication	Confidence in travelling alone	Ability to behave appropriately
Agoraphobia					•	
Anxiety	•	•	•	•	•	
Bipolar disorder	•	•	•	•	•	
Depression			•	•	•	
OCD						•
Psychosis		•	•			•
Schizo-affective disorder		•	•		•	•
Schizophrenia		•	•	•		•

A number of the conditions mentioned above can include memory impairment:

- ADHD<sup>56</sup>;
- Dementia<sup>57</sup>;

<sup>52</sup> NHS Choices, Health A-Z - Conditions and treatments, **Schizophrenia**, available from <http://www.nhs.uk/conditions/Schizophrenia/Pages/Introduction.aspx>.

<sup>53</sup> Rethink Mental Illness, **Schizophrenia**, available from <https://www.rethink.org/diagnosis-treatment/conditions/schizophrenia>.

<sup>54</sup> Mental Health Foundation, **Schizophrenia**, available from <https://www.mentalhealth.org.uk/a-to-z/s/schizophrenia>.

<sup>55</sup> Bridges Sally, **Mental health problems**, Chapter 2 in Volume 1 of the Health Survey for England 2014, Health, Social Care and Lifestyles, Health and Social Care Information Centre (2015), available from <http://content.digital.nhs.uk/catalogue/PUB19295/HSE2014-ch2-mh-prob.pdf>.

<sup>56</sup> See note 32.

<sup>57</sup> NHS Choices, Health A-Z - Conditions and treatments, **Memory loss (amnesia)**, available from <http://www.nhs.uk/conditions/memory-loss/Pages/Introduction.aspx>.

- Dyslexia<sup>58</sup>.

Other causes of memory loss include the following<sup>59</sup>:

- A stroke;
- A severe head injury;
- An underactive thyroid;
- Vitamin B1 (thiamine) deficiency;
- A brain tumour.

Memory loss tends to be higher in old age, with about 8% of those aged 75 and over having this impairment compared with 3% of those aged 35-74, and 2% of people aged 16-34<sup>60</sup>.

It is clear from the number of people affected by the various conditions that a significant proportion of the population have some form of mental impairment. Of course, some people have more than one condition, so it is not possible to calculate the total number of people affected by simply summing all the numbers of people with each condition. For example, 25-40% of people with learning disabilities have mental health problems<sup>61</sup>. The prevalence rate of a diagnosable psychiatric disorder has been found to be 36% in children and adolescents with learning disabilities, as opposed to 8% in those who do not have a learning disability. These young people are 33 times more likely to be on the autistic spectrum than those without a learning disability. Some people with Down's syndrome and some people with autism have a learning disability<sup>62</sup>. Also there may be people with both mental and physical impairments: for example, nearly a third of people with long-term physical conditions have a concurrent mental health condition such as anxiety or depression<sup>63</sup>.

In this section some of the possible effects of mental impairments on the mental skills used in travelling have been considered. There are several elements of the skills that may be affected: some impairments affect the ability to recall and perceive information and then process it. Others affect the person's ability to communicate with other people or the ability to behave in a way that is appropriate for the person's age. In the next section empirical evidence on the effects of mental impairments on travelling will be examined.

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<sup>58</sup> NHS Choices, Health A-Z - Conditions and treatments, **Dyslexia – Symptoms**, available from <http://www.nhs.uk/Conditions/Dyslexia/Pages/Symptoms.aspx>.

<sup>59</sup> See note 57.

<sup>60</sup> Office for Disability Issues, **Life Opportunities Survey, Wave 1 Results, 2009/11** (2011), available from <https://www.gov.uk/government/statistics/life-opportunities-survey-wave-one-results-2009-to-2011>.

<sup>61</sup> Foundation for People with Learning Disabilities, **Learning disability statistics: mental health problems**, available from <https://www.mentalhealth.org.uk/learning-disabilities/help-information/learning-disability-statistics-/187699>.

<sup>62</sup> See note 24.

<sup>63</sup> Naylor C, Parsonage M, McDaid D, Knapp M, Fossey M and Galea A, **Long-term conditions and mental health: The cost of co-morbidities**, The King's Fund and Centre for Mental Health (2012), available from [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf).

## 4 Travel by people with a mental impairment

### 4.1 Introduction

A number of aspects of making a journey have already been discussed in this report including planning the journey, having the ability to find the way, obtaining information, interacting with other people and being able to cope with disruption. Many of these depend on the mode of travel chosen. However, there are a number of more general issues that need to be considered, including having the confidence to leave home to make any journey.

Research with groups of people who have mental impairments has identified some specific problems that some of them have when travelling. It should be recognised that the evidence on this topic is limited. As Rosenqvist and colleagues<sup>64</sup> point out, it is challenging to develop research methods suitable for use with some people with mental impairments. It may not be practical to use instruments such as travel diaries and there may be challenges in communicating with people who have difficulty in expressing themselves verbally or in writing. Nonetheless, there is information which indicates what the barriers are and gives pointers to possible solutions.

The barriers that hinder (or prevent) travel by people with learning disabilities include the following<sup>65</sup>:

- Poor attitudes by staff, such as insensitive challenging of people about eligibility for certain concessions;
- Poor accessibility of some information about transport: some bus timetables and routes are difficult to understand, for example;
- Safety issues because of the risk of abuse and hate crime, plus a fear of being alone;
- Cost because many people have low incomes and there have been changes in the eligibility for some travel concessions for disabled people including people with mental impairments;
- Some concessions are not available at peak times which restricts the ability to work;
- Physical access which means that they are unable to use some modes of transport.

Beart and colleagues<sup>66</sup> conducted five focus groups at five establishments in Dudley which provide specialist services to people with a learning disability. 29 people took part, all with adequate comprehension and communication skills to participate. The survey identified many activities that they wanted to try that they were not currently doing, for example, night-clubbing, theatre, concerts and sport. The two main barriers were the lack of transport and the lack of a carer or friend to support them. Lack of money was not, in general, seen as a

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<sup>64</sup> Rosenqvist J, Risser R, Iwarsson S and Ståhl A, Exploring Mobility in Public Environments among People with Cognitive Functional Limitations—Challenges and Implications for Planning, *Mobilities*, **5** (2010), 131-145, available from <http://www.tandfonline.com/doi/full/10.1080/17450100903435011#abstract>.

<sup>65</sup> Callanan S (Mencap), Individual communication to author 18 February 2015.

<sup>66</sup> Beart S, Hawkins D, Kroese Biza S, Smithson P and Tolosa I, Barriers to accessing leisure opportunities for people with learning disabilities, *British Journal of Learning Disabilities*, **29** (2001), 133-138, available from <http://onlinelibrary.wiley.com/doi/10.1046/j.1468-3156.2001.00109.x/pdf>.

barrier. 70% of activities that they did and 83% of those that they wanted to do, involved some form of travel.

People with dyslexia sometimes have the following difficulties when travelling<sup>67</sup>:

- Listening linked with difficulty in processing the information received at the same time;
- Numerical processing, for example, reading a bus number correctly;
- Reading, especially if the information is presented all in upper case letters;
- Speech, because of difficulties in being able to express a verbal request for information;
- Spelling, especially at the pre-trip planning stage;
- Wayfinding, particularly at interchanges; some people may feel totally lost and unable to relate themselves to other objects; others with less severe problems may have difficulty distinguishing between concepts with names or labels that represent different positions in space, such as 'left' and 'right' or 'north' and 'south'.
- Emotional effects, for example frustration, nervousness, lack of confidence and low self-esteem, and feelings of inferiority, confusion and embarrassment.

Six focus groups with people with dyslexia containing a total of 52 participants recruited through dyslexic support groups were conducted by Lamont and colleagues<sup>68</sup>. They found that learning was an important part of the travel process with some people doing a dry-run (possibly with someone else) before making an important journey to learn visual clues and to avoid having to read signs, street names and numbers.

More generally, understanding route maps, timetables and fares may be difficult for people with various mental impairments because of their compromised literacy and numeracy skills<sup>69</sup>. Familiarity with bus numbers, routes and times helps to make journeys as stress free as possible, so minimising the disruption of established routines can be very important for some people with mental health support needs<sup>70</sup>.

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<sup>67</sup> Lamont D, Kenyon S and Lyons G, Dyslexia and mobility-related social exclusion: the role of travel information provision, **Journal of Transport Geography**, 26 (2013), 147–157, available from <http://www.sciencedirect.com/science/article/pii/S0966692312002244>.

<sup>68</sup> See note 67.

<sup>69</sup> House of Commons Transport Committee, **Access to Transport for Disabled People**, Fifth Report of Session 2013–14 Volume I Report, together with formal minutes, oral and written evidence, available from <http://www.publications.parliament.uk/pa/cm201314/cmselect/cmtran/116/116.pdf>.

<sup>70</sup> Penfold C, Cleghorn N, Creegan C, Neil H and Webster S, **Travel Behaviour, Experiences and Aspirations of Disabled People**, Report produced for the Department for Transport (2008), available from <http://webarchive.nationalarchives.gov.uk/20091003125851/http://www.dft.gov.uk/pgr/scienceresearch/social/travelbehaviours>.

There are ways in which accessing transport can be difficult for people with dementia<sup>71 72 73</sup>:

- A person with dementia may become frustrated because he or she hears and understands information but cannot get their body or brain to react to it;
- Aggression and anxiety may be exacerbated when in an unfamiliar environment; disorientation caused by, for example, a large car park, may lead to the person with dementia becoming aggressive or anxious; this may make it impossible for a person with dementia to be left in a car alone (or to be dropped off on the street while the car is being parked elsewhere);
- Poor balance and spatial awareness may mean that the person with dementia goes into defence or flight mode when approached suddenly and is deemed as aggressive; they may have hallucinations;
- Confusion and memory loss means that some carers will not let a person with dementia go out alone; people with dementia often feel compelled to wander about; hence making a trip out with car near to the destination reduces the risk of the person with dementia being lost;
- Problems with perception and comprehension may make it difficult for a person with dementia to make an unfamiliar journey unaccompanied or to cope with changes to the journey such as delays and cancellations; this can make stepping in or out of a car or bus difficult;
- Misinterpreting environments due to visiospatial perceptions may lead to increased risk of falls;
- When travelling by public transport, there may be difficulty co-ordinating the processes such as managing the multiple steps required to buy a ticket, correctly sequencing the steps to find the train, and logic such as finding seats and reading timetables;
- People with dementia usually have to give up driving and so become more reliant on public transport or transport provided by others;
- Other people may speak loudly thinking that the person with dementia is deaf whereas he or she may not have understood the information given or request made;
- Because dementia is a hidden disability, it may not be apparent to others;
- Sometimes staff mistake the symptoms of dementia for alcohol intoxication;
- Some people with dementia do not realise that they may be eligible for travel concessions or passenger assistance;
- Some people with dementia have incontinence;

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<sup>71</sup> Chandaria K and O'Hara J, Social Isolation and transport – how community transport can help, presentation at the Community Transport Association Annual Conference, 26 November 2014, available from <http://www.ctonline.org.uk/UserFiles/Docs/Events/England%20Policy%20Conference%202014%20presentations.pdf>.

<sup>72</sup> Alzheimer's Society, Alzheimer's Society response to Transport Committee Inquiry into transport for disabled people (2013), available from [http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1583](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1583).

<sup>73</sup> Bould E (Alzheimer's Society), Individual communication to author 3 February 2017.

- Dementia can lead to increasing physical frailty.

Having a stroke can cause some problems that affect travelling according to Logan and colleagues<sup>74</sup> who carried out semi-structured interviews with 24 people in Nottingham who had had a stroke to help understand attitudes and barriers to the use of transport:

- They could not travel as much as they wanted;
- Many could no longer drive;
- Many had a fear of injury or embarrassment from falling;
- There was a general lack of confidence about travelling;
- They had inadequate information about transport services, the cost of taxis and mobility scooters and environmental factors such as the weather.

Those who could drive, or who lived with someone who did, were the most positive about travelling. In an earlier study, Logan and colleagues<sup>75</sup> found that over half of the 42 people in the sample who had had a stroke saying that they wished to go out more often. The same team carried out an evaluation of an intervention involving a clinical assessment of the barriers to outdoor mobility and the negotiation of mobility goals and then delivered a package of measures which had a significant impact on outdoor mobility by people who had had a stroke, suggesting that there is latent demand for travel by at least some people with mental impairments<sup>76</sup>.

Some difficulties have been identified from a convenience survey of 203 people with mental health conditions<sup>77</sup>:

- Many people with mental health difficulties find it difficult to commit to a journey because their condition can fluctuate from one day to the next and so they cannot book in advance and obtain the cheapest fares;
- Many of them live on benefits so they cannot afford to travel as much as they would like; cuts in benefits mean that they may be able to get out less than previously;
- Many people with mental health difficulties do not realise that they may be eligible for assistance, such as concessionary travel passes for use on buses and that they can ask for Travel Assistance on trains;
- Overcrowding on buses and trains is very difficult for some people with mental health difficulties;
- They may be ignored by staff because they do not look disabled;

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<sup>74</sup> Logan P A, Dyas J, Gladman J R F, Using an interview study of transport use by people who have had a stroke to inform rehabilitation, **Clinical Rehabilitation**, **18** (2004), 703-708, available from <http://cre.sagepub.com/content/18/6/703>.

<sup>75</sup> Logan P A, Gladman J R F, Radford K A, The use of transport by stroke patients, **British Journal of Occupational Therapy**, **64** (2001), 261-264, available from <http://bjo.sagepub.com/content/64/5/261.full.pdf+html>.

<sup>76</sup> Logan P A, Gladman J R F, Avery A, Walker M F, Dyas J, and Groom L, Randomised controlled trial of an occupational therapy intervention to increase outdoor mobility after stroke, **British Medical Journal**, **329** (2004), 1372, available from <http://www.bmj.com/content/bmj/329/7479/1372.full.pdf>.

<sup>77</sup> Mental Health Action Group, **Mental Health & Public Transport** (2011), available from <http://www.derbyshiremind.org.uk/pdf/MHPublicTransportReport.pdf>.

- Dial-a-ride may not be available to them unless they also have a physical health problem;
- They may have difficulty understanding complex information at bus stops.

People diagnosed with agoraphobia find it very difficult or impossible to carry out certain activities which occur outside their home which can make any form of travel difficult and stressful<sup>78</sup>. These activities often involve going into crowded or public places, lifts, public transport or simply anywhere away from home where 'escape' or immediate access to help is not possible. They may also fear standing in queues, going onto bridges or sitting in any place where they feel 'trapped', such as at a hairdresser's or dentists. A companion for outings is often sought and may become essential.

Some general themes that emerge from these issues are reflected in the findings of Penfold and colleagues<sup>79</sup> in their interviews with nine people with mental health conditions selected using quota sampling. The key point is that confidence is crucial in making a trip. Three key factors are:

- **Routine and planning:** familiarity with bus numbers, routes and times helps make journeys as stress free as possible and minimise the disruption of established routines. The ability to plan trips is important; for young people: this means websites which they are able to use.
- **Safety and control:** this revolves around the choice of mode, travel companions and the attitudes of staff: sometimes when they feel very anxious they cannot use public transport and so perceive taxi as the only option. Sometimes travelling in confined spaces or at busy times can exacerbate feelings of anxiety and panic, so some modes are avoided, e.g. the Underground. Having a companion reduces anxiety. Staff attitudes can be an issue as they often seem rude and unhelpful, for example when offered a concessionary travel pass.
- **Affordability and finance** is very important because many have low incomes because they are not employed and so cannot afford to travel much.

Some of the issues affecting people with Autism Spectrum Disorder (ASD) were identified in two focus groups with nineteen parents and guardians of adults with ASD in New Jersey in the United States<sup>80</sup> :

- Safety concerns regarding their children with ASD not being able to utilise successfully transport modes other than being a car or school bus passenger due to their disability;
- Lack of reasonably priced transport options;

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<sup>78</sup> See note 39.

<sup>79</sup> See note 70.

<sup>80</sup> Feeley C, Deka D, Lubin A and McGackin M, **Detour to the Right Place: A Study with Recommendations for Addressing the Transportation Needs and Barriers of Adults on the Autism Spectrum in New Jersey**, Technical Report, Center for Advanced Infrastructure and Transportation, Rutgers University (2015), available from <http://vtc.rutgers.edu/detour-to-the-right-place/>.

- Lack of available transport options overall for people on the spectrum and a sentiment that many transport options are reserved for older adults;
- Lack of travel instruction during their children's transition period at school;
- Exclusion of transport from their children's Individualized Education Program (IEP).

One of the common themes of these lists of difficulties for specific mental impairments is problems with other travellers and staff. There is evidence that members of the general public are more comfortable interacting with people with physical or sensory impairments than with people with learning disabilities or mental health conditions, with 85% of adults believing that people with mental health conditions experience stigma and discrimination: the report 'Fulfilling Potential: Building a deeper understanding of disability in the UK today' says (on page 74) "Whilst understanding and tolerance of mental health conditions remained high in 2011, the proportion of adults voicing these tolerant attitudes has decreased since 1994"<sup>81</sup>. It also says that says people with mental health conditions and cognitive impairments are most likely to experience hate crime compared to people with other disabilities. Whitley and Prince<sup>82</sup> carried out a two-year qualitative study using in-depth interviews, focus groups and participant observation in the Gospel Oak neighbourhood in North London to examine the relationship between the fear of crime and mental health, and to assess the role that interventions may play in helping to overcome negative impacts arising from this fear. They found that people with mental health problems suffer disproportionately from fear of crime, especially women and older people. Fear of crime appeared to generate hyper-vigilance associated with ongoing worry and stress.

Whilst some people grow up with a mental impairment acquired at about the time of birth, and so learn gradually about how to travel, others may acquire a mental impairment suddenly. The effects of a sudden acquisition of a mental impairment upon travel patterns is illustrated by the survey carried out by Wendel and colleagues<sup>83</sup> in Sweden. They carried out a survey of 79 people living in the community who had had strokes and consequently had acquired cognitive functional limitations (CFLs). Of the 79 people in the sample, 23 ceased driving and 7 drove less, while 25 increased their travelling as a passenger in a private car or taxi. 11 ceased or decreased their travelling as a car or taxi passenger. 28 decreased or ceased travelling by public transport. Of these 28 people, 68% reported CFLs concerning comprehension, 64% reported CFLs concerning writing and 30% concerning the ability to cope with new environments and situations. Participants reporting decreased or ceased use of bus or train had more depression symptoms than those with increased use. Of the 79 in the

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<sup>81</sup> See note 2.

<sup>82</sup> Whitley R and Prince M, Fear of crime, mobility and mental health in inner-city London, UK, **Social Science & Medicine**, **61** (2005), 1678–1688, available from <http://www.sciencedirect.com/science/article/pii/S0277953605001589>.

<sup>83</sup> Wendel K, Ståhl A, Risberg J, Pessah-Rasmussen H, and Iwarsson S, Post-stroke functional limitations and changes in use of mode of transport, **Scandinavian Journal of Occupational Therapy**, **17** (2010), 162-174, available from <http://informahealthcare.com/doi/abs/10.3109/11038120902964450>.

sample, 25 walked less, 10 ceased walking and 7 walked more, possibly because of using other modes less.

Travel provides some positive experiences. For example, Penfold and colleagues<sup>84</sup> found that positive interactions with transport staff and other transport users helped some people with mental health conditions. Even though some people had fluctuations in the severity of their mental health support needs over time which meant that during ‘bad’ periods travelling could be very difficult, the ability to travel was very important to enable them to access services and social networks. Similarly, in their work in North London based on 32 participants randomly selected from a random sample of over 900 possible participants so that half of the 32 participants had a common mental disorder, Whitley and Prince<sup>85</sup> found that travel was vital for the personal well-being of the people with mental health issues. Taking part in work, education, social and leisure activities was described as therapeutic and important in giving them a sense of meaning and achievement in their lives. They found that, for residents with a common mental disorder, which is one characterised by anxiety and depressive symptoms, the Freedom Pass, the concessionary travel pass scheme in London, allowed them to access services, facilities and social support outside the neighbourhood which appeared to ameliorate some of the symptoms of their condition and prevent deterioration. Travel can provide therapeutic benefits for people with dementia by allowing them to gain access to the natural environment, to access arts and culture venues, to journey for reminiscence or to interact with people of different ages<sup>86</sup>

Whilst it is important that people with mental impairments are given the help that they need in order to travel, Iudici<sup>87</sup> argues that disabled people are sometimes described as ‘vulnerable’ which results in ‘protectionism’ and so their freedom is limited rather than expanded. In other words it is important to maintain a balance between providing the support that is necessary and being over-protective and preventing the person concerned from using the skills that they do have.

Having considered some of the general problems that make travel difficult for people with mental impairments, evidence on travel by the various modes by people will be considered in the rest of this section.

Before considering how people with mental impairments use various modes of travel, it is worth considering whether there are modes that they do not use, or use less than they would like. This is shown in Table 9 which is based on analysis of data from the Life Opportunities Survey<sup>88</sup>. It shows for five mental impairments, and for seven modes of travel, the percentage

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<sup>84</sup> See note 70.

<sup>85</sup> See note 82.

<sup>86</sup> See note 73.

<sup>87</sup> Iudici A, Implications on services and clinics, in **Safety and Security in Transit Environments: An Interdisciplinary Approach**, Vania Ceccato and Andrew Newton (Eds) (2015) (Palgrave Macmillan, Basingstoke and New York).

<sup>88</sup> See note 60.

of people with mental impairments that do not use each mode or use it less than desired. It also shows the percentage of people with no disability who do not use each mode or use it less than desired. This is important because it serves as a reminder that there may be reasons other than having an impairment that prevents people from travelling such as cost or lack of availability of the mode. Cost might prevent some people from using taxis and many people will not have access to the London Underground, and in some parts of Britain, there is very poor availability of local buses. Looking at the different modes for those with no impairment, it may seem surprising that there is such a small range of values from 45% for taxi or minicab to 51% for the Underground, and if the latter is excluded because of its limited availability, the range is from 45% to 48%.

Table 9 Percentage of people with mental impairments that do not use each mode or use it less than desired<sup>89</sup>

	Type of mental impairment					
	None	Learning	Intellectual	Memory	Mental health	Behavioural
Private motor vehicle	46	62	83	55	47	73
Local bus	48	58	71	50	44	64
Long distance bus or coach	48	60	78	53	48	73
Underground	51	60	75	51	47	70
Local train	47	57	73	48	42	67
Long distance/intercity train	47	58	74	47	43	66
Taxi or minicab	45	54	71	42	38	65

Turning to the mental impairments in the table, it will be noticed that there are five compared with the four used by Office for National Statistics<sup>90</sup> which are ‘Learning or understanding or concentrating’, ‘Memory’, ‘Mental health’ and ‘Socially or behaviourally’. The term ‘Learning or understanding or concentrating’ may be regarded as equivalent to the two categories ‘Learning’ and ‘Intellectual’ in Table 9. Once again, the range across the modes for each impairment is relatively small, but there are interesting variations across the mental impairments. In fact, they are in the same order all across the modes, which suggests that it is the impairment rather than the characteristics of the mode that causes the barrier. The highest proportions are for intellectual impairments, which include dementia and traumatic brain injury, then behavioural such as autism, then learning impairments, memory and then mental health. In fact the figures for mental health are lower than for people with no impairment. This may be for combination of reasons: many people with mental health issues have fluctuations in their condition which means that they can travel one day but not on another, and some of them may not be employed and do not have as much need to travel, or

<sup>89</sup> Source: Department for Transport, **The Impact of a Person's Impairment when Accessing Transport and the Social and Economic Losses as a Result of Restricted Access**, Rapid Evidence Review carried out for the Department for Transport by Integrated Transport Planning Ltd and Plymouth University (2016), using data from the Life Opportunities Survey.

<sup>90</sup> See note 14.

they may have lowered their expectations. This does not mean that they are not entitled to travel, just that the problems of overcoming the barriers to travel may be more complex than they appear at first sight.

#### 4.2 Walking

As discussed in Section 2, the main mental skills required to walk relate to wayfinding: understanding information from signposts and other visual clues plus the need to have the confidence to travel alone.

Lemoncello and colleagues<sup>91</sup> compared the navigational performance of 18 adults with acquired brain injury (ABI) with a control sample matched for gender, age and education. Over half of the participants with ABI had psychiatric diagnoses of depression. The participants were asked to follow written instructions with landmark, cardinal and left/right directions at four locations, and were measured in terms of accuracy, directness, stated confidence and preference. (Cardinal directions involve asking the traveller to face north, south, east or west). The authors argue that there are three critical points along a route where special attention is required: the origin, choice points and the destination. Compared with the control sample, the participants with ABI performed with the greatest proportion of errors and hesitancy when following cardinal instructions. The differences between the two samples were minimized when they followed landmark directions. The researchers concluded that using landmarks was the best way to provide navigational information, and that the descriptions of the landmarks should be as unambiguous as possible. In a follow up paper<sup>92</sup>, the authors discuss ways of coping when lost. They found that providing a mobile phone was a useful way of providing reassurance and offering assistance when the participant was lost. They found that it was important to ask the participant to stop walking and remain at the current location while the phone helper provided assistance. The only successful way to re-orientate participants was found to be to provide landmark information which meant that the helper providing the information either had to know the area or be provided with appropriate information such as photographs. Street View images provided by Google Maps may be suitable for this purpose.

Providing directions by specifying landmarks is recommended for people with dementia, with signs provided at eye level rather than above it because they may not look upwards or be able to do so<sup>93</sup>

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<sup>91</sup> Lemoncello R, Sohlberg M M and Fickas S, How best to orient travellers with acquired brain injury: A comparison of three directional prompts, **Brain Injury**, **24** (2010), 541–549, available from <http://www.tandfonline.com/doi/full/10.3109/02699051003610425>.

<sup>92</sup> Lemoncello R, Sohlberg M M and Fickas S, When directions fail: Investigation of getting lost behaviour in adults with acquired brain injury, **Brain Injury**, **24** (2010), 550–559, available from <http://www.tandfonline.com/doi/pdf/10.3109/02699050903446807>.

<sup>93</sup> See note 73.

Risser and colleagues<sup>94</sup> carried out semi-structured interviews with people with cognitive functional limitations after having strokes plus participant observation during bus trips with 8 participants. They found having many places that the participants needed to go to within walking distance was very useful because it encouraged them to walk every day. Difficulties when out walking included the need to look down all the time in order to check the surface, the fear of walking into someone or something, and crossing the road at pedestrian crossings because they were afraid that the traffic signal would turn to red before they had crossed: sometimes they missed the bus because of the time it took crossing the road.

Feeley and colleagues<sup>95</sup> examined the travel needs and barriers of adults on the autism spectrum in New Jersey, USA, by carrying out a survey between the middle of 2014 and early 2015, mainly on-line with a few responses returned by post. A convenience sampling design was used with 27 different avenues used to contact potential respondents including websites and contact lists maintained by various agencies and organizations. A total of 703 responses were obtained, but not all respondents answered all questions. 86.1% of the respondents were aged 18 to 29, 11.8% were aged 30 to 49, 2.1% were aged 50 to 64 and none were aged 65 or over. 86.3% lived with their parents. Only 2.5% lived alone. They identified a number of difficulties with walking, as shown in Table 10. Crossing the road seems to be the biggest issue, but wayfinding was also important.

Table 10 Aspects of walking found difficult for people on the autism spectrum in New Jersey, USA<sup>96</sup>

<b>Aspect of walking</b>	<b>Percentage of respondents finding this aspect difficult</b>
Judging the distance and/or speed of cars	45.2
Crossing a street	41.3
Dealing with distractions whilst walking	40.1
Too many cars or too much traffic	36.6
Difficulty determining directions/route	35.1
Walking in areas without sidewalks (on grass or in streets)	27.5
Other	12.2
Too many people on the sidewalk	9.1

There seems to have been rather limited research into wayfinding when walking by people with mental impairments. The main message seems to be that reassurance is required in the form of clear, understandable information whether it is in the form of physical signs or provided by mobile phone, and that the landscape needs to be legible, with clear landmarks and not too many distractions.

<sup>94</sup> Risser R, Iwarsson S and Ståhl A, How do people with cognitive functional limitations post-stroke manage the use of buses in local public transport? **Transportation Research F**, 15 (2012), 111–118, available from <http://www.sciencedirect.com/science/article/pii/S1369847811001094>.

<sup>95</sup> See note 80.

<sup>96</sup> Source: see note 80.

### 4.3 Bus

Bus provides the opportunity to make local trips that are longer than can reasonably be walked, and for many people without a car, it may be the only practical way to travel to the shops or the doctor, including many people with mental impairments. For example, in focus group discussions with disabled people including two with people with learning disabilities and one with people with mental health problems carried out in the West Midlands<sup>97</sup>, it was found that, for many of the participants, bus was the only form of transport that they could use. Some of those who could drive said that travelling by bus removed the inconvenience, uncertainty and high cost of parking particularly at hospitals and in town centres. For the participants with learning disabilities, it was the only form of public transport that they could use independently after extensive travel training, which gave them highly-valued independence, since it enabled them to access activities and facilities that they might not otherwise be able to use. The lack of buses in the evening and at weekends led to social isolation for some respondents in the survey of 203 people with mental health issues carried out by the Mental Health Action Group<sup>98</sup>. It also led to the frequent use of taxis, despite the high cost because of buses running late, particularly in the evening, in the West Midlands<sup>99</sup>. In their focus groups with people with learning disabilities, Beart and colleagues<sup>100</sup> found that issues about public transport included the service not being regular enough and long waiting times leading to people missing their leisure pursuits. Low frequency and late running buses can cause difficulty for people with dementia who need to access health services because they have to travel several hours early or incur high costs using taxis<sup>101</sup>.

Table 9 showed that many people with mental impairments do not use local bus or use it less than they desire. Table 11 shows the main reasons why this is the case. The table shows the top five reasons for not travelling by bus, indicating the percentage of respondents giving each response. It can be seen that for people without a mental impairment 'Transport unavailability' is the top reason, followed by 'Cost' and 'Other reasons'. For most people with mental impairments the top reason is 'Anxiety/lack of confidence', which is mentioned by over 10% of respondents in each case, including 28% of those with mental health conditions and 21% of those with behavioural impairments. For all the mental impairments, except intellectual impairments, more people cited 'cost' than the population without impairments. Over 10% of people with memory impairments and those with mental health impairments mentioned 'Difficulty getting in and out of the bus'. These may be related to physical disabilities in some cases, but may well be difficulties interacting with the driver. Similarly, over 10% of people in these groups mentioned 'Difficulty to getting to stop' and 'Getting from stop to destination', which may be difficulties walking of the type discussed in Section 4.2.

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<sup>97</sup> SYSTRA, **Research into travel requirements of older and disabled people**, Report on work carried out for CENTRO (2014).

<sup>98</sup> See note 77.

<sup>99</sup> See note 97.

<sup>100</sup> See note 66.

<sup>101</sup> See note 73.

‘Overcrowding’ is the third reason on the list for people with intellectual and behavioural impairments. It was cited by 11% of those with mental health issues and 5% of those with a learning impairment (but was not in the top five reasons), compared with less than 3% of those with no impairment.

Table 11 Main reasons for not using local bus or using it less than desired by people with mental impairments<sup>102</sup>

Rank	Type of impairment					
	None	Learning	Intellectual	Memory	Mental health	Behavioural
1	Transport unavailable 11	Cost 16	Anxiety/lack of confidence 7	Anxiety/lack of confidence 17	Anxiety/lack of confidence 28	Anxiety/lack of confidence 21
2	Cost 7	Transport unavailable 11	Cost 5	Difficulty getting in or out of the bus 17	Cost 26	Cost 15
3	Other reasons 7	Anxiety/lack of confidence 10	Over-crowding 4	Cost 15	Transport unavailable 14	Over-crowding 8
4	Delay and disruption to service 4	Other reasons 7	Transport unavailable 4	Difficulty getting to stop 14	Difficulty getting in or out of the bus 13	Delay and disruption to service 7
5	Too busy/not enough time 4	Delay and disruption to service 7	Attitudes of passengers 3	Difficulty getting from stop to destination 13	Difficulty getting from stop to destination 12	Fear of crime 6

Note: The figures are the percentage of people with the mental impairment citing the reason shown. ‘A health condition, illness or impairment’ and ‘A disability’ have not been included as reasons in the table since the emphasis here is on the more specific reasons.

From Table 11 it seems that anxiety and lack of confidence is the top reason preventing people with mental impairments from travelling by local bus. Getting to and from the stop and getting in or out are also issues, the former probably due to wayfinding issues, the latter possibly to do with difficulties interacting with the driver. These latter issues are illustrated in Table 12, which uses data from the National Bus Passenger Survey (NBPS) to show satisfaction with the bus driver for four categories of people with mental impairment: learning, memory, mental health and behavioural (labelled ‘socially’ in NBPS).

<sup>102</sup> Source: see note 89.

Table 12 Bus users with mental impairments satisfied with the bus driver (%)<sup>103</sup>

	No impairment	Has an impairment	Type of mental impairment			
			Learning	Memory	Mental health	Behavioural
Helpfulness and attitude	73	72	65	68	67	61
The greeting and welcome received	72	71	63	69	66	61

Table 12 shows that over 70% of people with no disability are satisfied with the helpfulness, attitude and greeting of bus drivers and that the overall average for people with an impairment is very similar. However, lower proportions of people with mental impairments are satisfied, particularly those with a behavioural impairment such as autism. Those with learning impairments have the second lowest levels of satisfaction. There is evidence that some bus drivers do not behave appropriately with people with mental impairments. In their focus groups work in the West Midlands<sup>104</sup> SYSTRA found a number of examples, including drivers being rude to passengers, acting in an unfriendly manner, being unable to communicate with passengers with learning disabilities especially by drivers whose first language was not English, lack of knowledge of the bus route and timetables, and taking advantage of some passengers with learning disabilities, for example by overcharging them or giving the incorrect change. In other cases, drivers did not stop at request stops for people with learning disabilities. Drivers departing before a person with dementia has taken their seat can cause difficulties<sup>105</sup>.

In their focus groups with people with dyslexia, Lamont and colleagues<sup>106</sup> found that staff were unaware of the problems caused by dyslexia, and that there was a reluctance by some participants to disclose their condition. In the USA, Sohlberg and colleagues<sup>107</sup> found in their study of six people with severe acquired brain injuries that unhelpful bus drivers were a barrier to travel. Some extreme examples of bad behaviour by bus drivers were identified by Chan and Suen<sup>108</sup> who cite the cases of two 12 year olds with learning impairments in Canada who had confrontations with bus drivers. In one case the boy was threatened with bodily

<sup>103</sup> Passenger Focus, **National Bus Passenger Survey results**, Autumn 2014.

<sup>104</sup> See note 97.

<sup>105</sup> See note 73.

<sup>106</sup> See note 67.

<sup>107</sup> Sohlberg M M, Todis B, Fickas S, Hung P-F, and Lemoncello R, A profile of community navigation in adults with chronic cognitive impairments, **Brain Injury**, 19 (2005), 1249–1259, available from <http://dx.doi.org/10.1080/02699050500309510>.

<sup>108</sup> Chan H K P and Suen L, Mobility for travelers with attention deficit hyperactivity disorder and learning disabilities: challenges and solutions, **Transportation Research Board 92nd Annual Meeting**, Washington DC (2013), available from <http://amonline.trb.org/2013-1.264263/13-4646-1-1.276644>.

harm and in the other the girl was ordered by a supervisor to leave the bus. In both cases, other passengers protested about the behaviour of the driver.

Another area of difficulty can be the behaviour and attitudes of other passengers. As Table 13 shows, the proportion of people with mental impairments who were concerned about the behaviour of other passengers was much higher than that for people with no disability and the average across all disabilities. In their work in the West Midlands, SYSTRA<sup>109</sup> found that the behaviour by other passengers that caused concern for people with learning disabilities included smoking, drug taking, playing loud music and bullying, as did the behaviour of school children, particularly in large groups, shouting and banging on the buses. Some people with mental health problems, for example, those with schizophrenia, particularly found loud music a problem. The attitudes of other passengers can cause difficulty for people with dementia, for example if they are impatient if the person with dementia is slow paying for their ticket or by not giving up a priority seat<sup>110</sup>.

Table 13 Bus users with mental impairments who find the behaviour of other passengers a concern (%)<sup>111</sup>

No impairment	Has an impairment	Type of mental impairment			
		Learning	Memory	Mental health	Behavioural
6	8	14	13	10	14

In Sweden, Rosenkvist and colleagues<sup>112</sup> carried out interviews with 27 experts who were occupational therapists, lay assessors and representatives from special interest groups and semi-structured interviews and participant observation of public transport users with cognitive functional limitations (CFI). They found that some of the participants asked fellow travellers for information, for example, on where to wait for the bus. The view of the experts was that some people with cognitive impairments are happy to ask for information and spend time with people that they do not know while others found it difficult because they had communication difficulties and because they lacked self-confidence.

A related problem is overcrowding on buses. SYSTRA<sup>113</sup> found that it was an issue for some people with mental health problems, particularly when it made boarding and alighting difficult. In the survey by the Mental Health Action Group<sup>114</sup>, the availability of buses was an

<sup>109</sup> See note 97.

<sup>110</sup> See note 73.

<sup>111</sup> Source: see note 103.

<sup>112</sup> Rosenkvist J, Wendel K, Stahl A, Risser R and Iwarsson S, Public transport planning from the perspective of people with cognitive functional limitations, **International Conference on Mobility and Transport for Elderly and Disabled Persons (TRANSED 2007)**, Montreal, Canada, available from <http://www.transedconferences.com/Transed2007/pages/1086.htm>.

<sup>113</sup> See note 97.

<sup>114</sup> See note 77.

issue because the low frequency of services meant that many buses were overcrowded which made travelling difficult for many respondents.

Carmien and colleagues<sup>115</sup> argue that, for some people with mental impairments, learning a new route may interfere with knowledge about previously learned routes.

The House of Commons Transport Committee found in the evidence presented to it, that those with learning disabilities and other cognitive impairments, and those with some mental health impairments, suffer when there is a lack of information accessible to them when waiting for or travelling on buses<sup>116</sup>. They report that there is concern about a lack of simple and clear information about the journey at many bus stops, but the issue most frequently raised was the lack of AVI on buses. The issue of anxiety and lack of confidence in travelling by bus shown in Table 7 can be addressed partly by the provision of information in an appropriate format. For example, in their work in Sweden with people with CFI, Rosenkvist and colleagues<sup>117</sup> found that the key factors for the users were the meaning and use of information and the presence and actions of other people as barriers or enablers. They reported that people with CFI may find it difficult to retain all the details about their trip and so clear and detailed information is required, especially about how to buy a ticket on the bus. They found cases of people who had to change modes or vehicles in the course of the journey who found it so exhausting to establish what to do that they were not able to carry out the task which was the rationale for the journey when they eventually arrived. They observed that the participants used a variety of ways of obtaining information including reading displays on the bus, listening to audible announcements and asking the driver, which suggests that information should be presented in a variety of ways. However, they acknowledge that there is a risk of information overload which means that a traveller with cognitive impairments cannot sort out the relevant information.

One group that has particular problems interpreting information is people with dyslexia. In their focus groups with people with dyslexia, Lamont and colleagues<sup>118</sup> identified the following problems in using public transport:

- Auditory information which was too complex, which meant that some participants felt excluded from some routes and modes;
- Timetable problems which included font style, font size, colour contrast, use of 24h clock, information presented horizontally, and use of glossy paper;
- Electronic variable message signs, including scrolling which was often perceived as too rapid for the information to be assimilated;

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<sup>115</sup> See note 10.

<sup>116</sup> See note 69.

<sup>117</sup> See note 112.

<sup>118</sup> See note 67.

- Web-based travel information, often because of the wealth of information presented, and the need to input the names of origins and destinations spelt correctly; lists of similar place names can also present problems;
- Obtaining information from other people, often caused by staff being unaware of the problems caused by dyslexia, and a reluctance of some participants to disclose their condition;
- On-board information, with some people unable to assimilate information displayed visually, which means relying on audible information, which is not always available or clear.

The Mental Health Action Group<sup>119</sup> found that many of the respondents in their survey liked electronic information because it provided reassurance; they also liked audio announcements as it could be difficult to read information if they were feeling unwell; information at bus stops is very useful but, for many people, it needs to be in large print and clear. People with dementia can be confused by electronic information displays that spread information over several pages, saying, for example, 'Page 1 of 4'<sup>120</sup>.

Obtaining information can be particularly difficult when the service is disrupted or changes are made to services for people with mental health issues: SYSTRA<sup>121</sup> found that lack of information, for example, the bus being late with no explanation, caused distress to some people with mental health conditions, possibly because they could not think logically about why this should be the case, as did changes to bus routes and timings. Changes to routes and timetables caused problems for people with learning disabilities who had received travel training in which they had memorised particular routes and times because they had to have further training to understand the changed routes or times.

Table 7 showed that the cost of bus travel was a deterrent for some people with mental impairments. Because many people with mental health issues live on benefits they cannot afford to spend much on travelling and so the concessionary travel pass offering free off-peak bus travel is very valuable. 41% of those surveyed by the Mental Health Action Group<sup>122</sup> had a pass (compared with 80% of older people). SYSTRA<sup>123</sup> found that in the West Midlands, the complexities of the rules for a pass giving free travel caused difficulties for some people with learning disabilities because often they did not fully understand the regulations and procedures, such as time restrictions on their use and how to renew their pass.

The range of issues that may be barriers to using public transport is illustrated in the convenience survey of 703 adults on the autism spectrum in New Jersey, USA, by Feeley and

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<sup>119</sup> See note 76.

<sup>120</sup> See note 73.

<sup>121</sup> See note 97.

<sup>122</sup> See note 77.

<sup>123</sup> See note 97.

colleagues<sup>124</sup>, who received 195 responses from people who used public transport and 310 from those who did not. Table 14 summarises the barriers identified. Whilst the use of public transport was not very high, bus was used more than suburban rail or light rail. Some of the reasons would apply to all users, such as lack of availability of the service and unreliability, but worries about the helpfulness and friendliness of the driver and the attitudes of other passengers come high on the list. The top reason, cited by over half of the users, was difficulty with planning the trip. Another major issue was difficulty getting to the bus stop or railway station without help.

Table 14 Barriers to using public transport cited by users and non-users of the mode on the autism spectrum in New Jersey, USA <sup>125</sup>

<b>Barrier</b>	<b>Percentage of users citing this barrier</b>	<b>Percentage of non-users citing this barrier</b>
Difficulty with planning a public transport trip	51	15
Public transport service is not available to destinations	48	17
Worried about how other public transport passengers will treat the individual	44	14
Worried about public transport driver friendliness/helpfulness	43	14
Difficulty getting to the bus stop/railway station without help	41	15
Public transport is not available when needed	39	12
Worried about crime on public transport	30	10
Public transport is not reliable	27	8
Too many trip transfers needed	26	7
Worried about finding a seat on a bus/train	22	6
Other barriers	20	8
Parents/guardians do not want the individual to use public transport	17	6
Difficulty getting on/off buses and trains	16	9
Public transport fare is too high	13	3

The difficulties encountered by a child with autism in using public transport have been outlined by Ambitious about Autism<sup>126</sup>. These include the fact that a child with autism may communicate using a picture system or sign language which most commuters will not understand. Even if he or she has some verbal skills, holding a conversation can be difficult and approaching strangers, to ask for information, may be very intimidating. This make a child with autism feel isolated in public. A child with autism may lack flexibility in their thinking and

<sup>124</sup> See note 80.

<sup>125</sup> Source: see note 80.

<sup>126</sup> Ambitious about Autism, **Using public transport**, available from <https://www.ambitiousaboutautism.org.uk/understanding-autism/out-and-about/using-public-transport>.

so find it difficult to understand why a bus or train is late, or recognise the correct bus if the logo has been changed or it is covered in advertisements. A further issue is that they may lack a sense of danger because they cannot always predict the consequences of their actions, such as jumping off a moving bus. Autism can be associated with increased sensitivities. This means that sounds, smells and sights can either mesmerise or horrify the child. Some people with autism are uncomfortable touching or being too close to other people which means travelling on overcrowded bus or train can cause significant levels of stress. Some children with autism have obsessive or inflexible behaviour patterns which make it difficult to switch from one activity to another, for example from sitting on the bus or train to alighting from it, which might mean they miss their stop. Some children with autism may bond to particular experiences and so, for example, may need to sit in the same seat on the bus or train and find it difficult if they cannot. A number of suggestions of ways of addressing some of these issues are presented:

- Make planning and timing as accurate as possible, for example by using journey planners to establish walking and waiting times at the planning stage to give a sense of predictability and using mobile phone apps to track the bus or train to reduce uncertainty during the journey;
- If possible, buy a season ticket for the child in order to reduce the need for negotiation to buy individual tickets;
- If the child has hearing sensitivities, buy noise-cancelling headphones or ear defenders;
- Obtain travel training for the child if he or she is able to follow instructions reasonably well;
- Avoid crowds as far as possible;
- If appropriate, use visual support in the form of pictures to explain the journey in advance;
- Offer incentives, but ensure that the child has seen the incentive in advance and that the reward is provided within the child's attention span after the journey;
- If the child has tantrums, it may be useful to have some autism awareness cards to show to fellow travellers to help explain what is happening.

Even though much can be done to make bus travel easier, it should be borne in mind that some people with mental impairments are unlikely to travel by bus very much. This was found in the case of people with severe acquired brain injuries by Sohlberg and colleagues<sup>127</sup> who concluded that even with easy access to public transport, people with cognitive disabilities tended to make few independent bus trips, in part because they have trouble initiating trips and remembering destinations.

#### **4.4 Coach or long distance bus**

A similar form of transport is coach, which provides long distance travel, often at a lower fare than travelling by train. Table 15 shows the main reasons for not using coach as much as

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<sup>127</sup> See note 107.

desired. Despite the relatively low fares, 'Cost' is the main reason for low usage of it, for people with no impairment and four out of five of the groups of people with mental impairments, and second for the other one. However, 39% of those with a mental health condition cite cost as an issue, compared with 10% of those without an impairment. For those with mental impairments 'Anxiety/lack of confidence' is the top reason for people with behavioural impairments and second for all the other groups of people with mental impairments. 'Overcrowding' comes out high on most of the lists. Difficulties getting to and from the coach stop or station and getting in or out of the coach also feature fairly highly on the lists.

Table 15 Main reasons for not using long distance bus or coach or using it less than desired by people with mental impairments<sup>128</sup>

Rank	Type of impairment					
	None	Learning	Intellectual	Memory	Mental health	Behavioural
1	Cost 10	Cost 24	Cost 8	Cost 25	Cost 39	Anxiety/lack of confidence 21
2	Other reasons 10	Anxiety/lack of confidence 10	Anxiety/lack of confidence 5	Anxiety/lack of confidence 18	Anxiety/lack of confidence 29	Cost 20
3	Transport unavailable 4	Other reasons 9	Over-crowding 4	Difficulty getting in or out of the transport 11	Over-crowding 14	Over-crowding 7
4	Too busy/not enough time 4	Overcrowding 6	Other reasons 3	Other reasons 10	Other reasons 11	Other reasons 6
5	Over-crowding 3	Transport unavailable 5	Difficulty getting in or out of the transport 3	Difficulty getting to stop or station 10	Difficulty getting in or out of the transport 9	Fear of crime 6

Note: See notes under Table 11.

#### 4.5 Paratransit

In Britain, the term 'paratransit' covers specialist collective travel by road vehicles that are smaller than buses. It can include community transport and dial-a-ride, which enables people in certain categories, including disabled people, to book a door-to-door journey with other people making similar journeys.

In its work in the West Midlands with people with learning disabilities and mental health problems SYSTRA<sup>129</sup> found that 'Ring and Ride' was viewed positively, in general, offering a

<sup>128</sup> Source: see note 89.

<sup>129</sup> See note 97.

way that people with learning disabilities could go out in the evening when they would be apprehensive about using buses. However, in their focus group discussions with people with a learning disability in Dudley in the West Midlands, Beart and colleagues<sup>130</sup> found that specialist transport was not always on time, and stopped at 22.00 which was a restraint to going out in the evening. They also found that 'Ring and Ride' does not cross local authority boundaries so the users could not visit some friends. Some dial-a-ride and community transport services will not take a person with dementia unless they are accompanied by a carer which discriminates against people who live alone or without carers<sup>131</sup>.

#### 4.6 Rail

The reasons for not travelling by train are shown in Tables 16 and 17: local train in the former, long distance or intercity train in the latter. For people without impairments the top two reasons for not using either form of rail are the cost and the lack of availability. Cost is the top reason for all the mental impairments for both types of rail, except for people with behavioural impairments using local rail where it is second. In all cases except intellectual impairments, the percentage of people deterred from using it on the grounds of cost is higher

Table 16 Main reasons for not using local train as much as desired by people with mental impairments<sup>132</sup>

Rank	Type of impairment					
	None	Learning	Intellectual	Memory	Mental health	Behavioural
1	Cost 8	Cost 17	Cost 5	Cost 20	Cost 31	Anxiety/lack of confidence 17
2	Transport unavailable 8	Transport unavailable 7	Anxiety/lack of confidence 5	Anxiety/lack of confidence 13	Anxiety/lack of confidence 23	Cost 14
3	Other reasons 3	Anxiety/lack of confidence 7	Transport unavailable 3	Transport unavailable 11	Overcrowding 11	Overcrowding 7
4	Difficulty getting to station 2	Difficulty getting to station 5	Overcrowding 2	Difficulty getting to station 9	Transport unavailable 10	Transport unavailable 6
5	Difficulty getting from station to destination 2	Overcrowding 5	Difficulty getting to station 2	Difficulty getting from station to destination 9	Difficulty getting to station 9	Difficulty getting to station 6

Note: See notes under Table 11.

<sup>130</sup> See note 66.

<sup>131</sup> See note 73.

<sup>132</sup> Source: see note 89.

than for those without an impairment. ‘Anxiety/lack of confidence’ comes in the top three reasons for all types of mental impairment for both types of rail. ‘Overcrowding’ comes in the top three for people with mental health and behavioural impairments for both types of rail. The key points are that anxiety/lack of confidence and overcrowding are significant factors, deterring people with mental impairments from making journeys. Cost tends to deter more people with mental impairments than those with no impairment. The exception to this is people with intellectual impairments which may be because they make so few trips (see Table 9). That may be because a significant proportion of them are elderly people with dementia who are not employed and so they have less need to travel than the general public and people with some other mental impairments.

Table 17 Main reasons for not using long distance / intercity train as much as desired by people with mental impairments<sup>133</sup>

Rank	Type of impairment					
	None	Learning	Intellectual	Memory	Mental health	Behavioural
1	Cost 15	Cost 26	Cost 10	Cost 29	Cost 44	Cost 21
2	Transport unavailable 3	Anxiety/lack of confidence 9	Over-crowding 5	Anxiety/lack of confidence 15	Anxiety/lack of confidence 22	Anxiety/lack of confidence 18
3	Other reasons 3	Over-crowding 6	Anxiety/lack of confidence 5	Difficulty getting in or out of the transport 10	Over-crowding 11	Over-crowding 7
4	Too busy/not enough time 2	Difficulty getting to station 5	Transport unavailable 4	Difficulty getting to stop or station 9	Difficulty getting to stop or station 9	Difficulty getting to stop or station 6
5	Over-crowding 2	Transport unavailable 4	Difficulty getting from station to destination; Difficulty getting to station; Lack of help or assistance 3	Difficulty getting from stop or station to destination 9	Difficulty getting from stop or station to destination 8	Other reasons 4

Note: See notes under Table 11.

Data from the National Rail Passenger Survey<sup>134</sup> which is conducted during a rail journey asking questions about that journey, permit exploration of the factors that make rail travel

<sup>133</sup> Source: see note 89.

<sup>134</sup> Passenger Focus, **National Rail Passenger Survey results**, Autumn 2014.

challenging for people with mental impairments. Whilst the total number of trips included is large at 54,927, the number by people with mental impairments is much smaller, ranging from 163 by people with learning disabilities to 877 by people with mental health conditions. For some questions, the numbers are smaller. This means that the results must be treated with some caution. Table 18 shows the percentage of rail travellers with mental impairments whose condition has an adverse ability on their ability to travel by rail, plus those with any impairment. Greater proportions of people with learning, memory and behavioural impairments find their condition has a major adverse effect on their ability to make rail journeys than all those with an impairment on average. Interestingly, fewer people with mental health issues find that their condition has an impact on their ability to travel by rail than the overall average for people with impairments.

Table 18 Percentage of rail travellers with mental impairments whose condition has an adverse effect on their ability to make journeys<sup>135</sup>

	Has an impairment	Type of mental impairment			
		Learning	Memory	Mental health	Behavioural
Yes a lot	8	12	15	6	11
Yes a little	44	40	42	40	41
All yes	52	52	57	46	52

People with dementia have a number of difficulties when travelling by rail such as forgetting where to get off the train, finding stations difficult to navigate, trying to access parts of the rail network not open to the public such as ramps at the ends of platforms or maintenance areas and failing to recognise dangerous places<sup>136</sup>. Unstaffed stations pose serious problems, because, for example, ticket machines can be very confusing for people with dementia. Similarly, driver only operation of trains means that there is nobody on board to assist the person if he or she is lost or confused.

All travellers have needs, for example, for information and facilities for ticket purchase, but some people with impairments have extra needs when they travel, as discussed in Section 4.1. Table 19 shows how many people with impairments feel their needs were satisfied on the rail journey, indicating satisfaction with the station and the trains separately. It can be seen that for all people with impairments, 67% felt the station met their needs, and 65% felt the trains did. A greater percentage of people with learning impairments felt that their needs were met. The group feeling least satisfied were the people with behavioural impairments, followed by those with mental health conditions.

<sup>135</sup> Source: See note 134.

<sup>136</sup> Bould E, Note on Issues and challenges for people living with dementia when travelling by rail.

Table 19 Percentage of people with mental impairments who are satisfied that their needs as a passenger are met<sup>137</sup>

	Has an impairment	Type of mental impairment			
		Learning	Memory	Mental health	Behavioural
Station	67	72	69	63	61
Trains	65	71	64	57	58

The survey carried for the Mental Health Action Group<sup>138</sup> shows that many people with mental health conditions find it difficult to commit to a journey on a particular day because of fluctuations in their condition and so they are unable to book in advance and so cannot obtain the cheapest fares. This is confirmed by Table 20 which shows that tickets were bought on the day of travel by nearly one quarter of the rail travellers with a mental health condition, compared with about half that number for the whole population and all people with an impairment. People with other mental impairments made fewer trips using a ticket bought on the day of travel, possibly because another person bought it in advance on their behalf.

Table 20 Percentage of people buying a rail ticket on the day of travel<sup>139</sup>

No impairment	Has an impairment	Type of mental impairment			
		Learning	Memory	Mental health	Behavioural
12	12	3	10	23	7

The perceived helpfulness and attitude of railway staff is shown in Table 21. It can be seen that, in general, station staff are seen as more helpful than those on the train. There is little difference between the ratings for those with an impairment and those with no impairment, except that more people with an impairment found the on-train staff unhelpful and with a poor attitude than people with no impairment. However, fewer people with mental impairments rated railway staff as helpful and more rated them as them as poor in terms of helpfulness and attitude than both those with no impairment and those with any impairment. The group with the greatest percentage giving low ratings to station staff is those with a behavioural impairment, whilst the group giving the lowest rating to on-train staff is those with a memory impairment. Given that the figures for those with an impairment is an average across all impairments, including those with mental impairments, it seems that staff are perceived as helpful by more people with impairments other than mental impairments than

<sup>137</sup> Source: See note 134.

<sup>138</sup> See note 77.

<sup>139</sup> Source: see note 134.

people with no impairment. This suggests that the training that railway staff receive needs more emphasis on the needs of those with mental impairments.

Table 21 Rating of the helpfulness and attitude of railway staff<sup>140</sup>

				Type of mental impairment			
		No impairment	Has an impairment	Learning	Memory	Mental health	Behavioural
At the station	Good	73	74	68	70	70	66
	Poor	8	9	15	15	10	16
On the train	Good	64	63	61	53	58	61
	Poor	9	12	14	28	14	21

Personal security is an important issue, with more people with an impairment being concerned than those without an impairment, as shown in Table 22. However considerably more people with learning, mental health and behavioural impairments have concerns. Fewer people with memory impairments have such concerns than all those with an impairment. It should be acknowledged that this table is based on small numbers of people with mental impairments (68 with a mental health condition, 18 with a learning impairment, 17 with a behavioural impairment and 11 with memory impairment).

Table 22 Percentage of people who had cause to worry about personal security whilst making a rail journey in the last six months <sup>141</sup>

		Type of mental impairment			
No impairment	Has an impairment	Learning	Memory	Mental health	Behavioural
9	18	32	13	24	24

In the study by SYSTRA<sup>142</sup> in the West Midlands, trains were liked by some people with mental health conditions because of the amount of space that they offered and because those trains with toilets on board eased anxiety about needing to use the toilet whilst travelling. Consistent audio announcements at railway stations and during the journey were liked because of the assurance that they provided for people with mental health problems.

Anxiety UK<sup>143</sup> has produced a note explaining how anxiety-related disorders are a mental health issue that prevent thousands of people from using trains. In particular, the note discusses the effects of agoraphobia, explaining that it is most commonly triggered by the sense of being trapped, or at risk of being trapped, regardless of the size of a space rather than a fear of open spaces which is a common perception. They argue that the redesign of

<sup>140</sup> Source: see note 134.

<sup>141</sup> Source: see note 134.

<sup>142</sup> See note 97.

<sup>143</sup> Anxiety UK, **Mental health and rail travel: accessibility for people with anxiety related disorders**, note based on survey results.

passenger trains over the last 30 years has turned the majority of train carriages into environments that are perceived as airless sealed units which is likely to cause extreme distress to some sufferers of anxiety related disorders. A number of issues and possible solutions are identified:

- Sealed windows, windows bolted shut, and windows which open only a few centimetres, which could be remedied by reintroducing one or more manually operable door with a fully openable window on every train, particularly in the front/and or rear carriages (with retrofitting where possible);
- Electronic doors which cannot be operated manually, which could be remedied by providing a manually operated door in one or more carriage in every train;
- Toilets with electronic doors, or sealed unit locking mechanisms, which could be addressed providing toilet doors with conventional, manually operated designs, using large lever disabled toilet lock designs which cannot fail causing entrapment;
- Extended periods stationary, particularly without announcement, updates or explanation;
- Tunnels, particularly extended or stationary periods, which could be overcome in some cases by minimising any stopping in tunnels by repositioning of signal points where necessary, and in by providing clear passenger information on which routes involve either long tunnels or a risk of stopping in a tunnel;
- Railway staff reacting insensitively to passenger requests, which could be overcome by appropriate staff training;
- Bus replacement services for interrupted train travel, which can be partially addressed by providing as much notice to passengers as possible if travelling by a replacement bus is necessary as part of the service has been interrupted and using a suitable bus with openable windows and regular stops;
- Lack of alert buttons, which can be addressed by installing them in every carriage, or, if this is not possible, by providing clear signage describing the procedures for vulnerable people experiencing an anxiety issue;
- Inconsistent journey information can cause anxiety, so clear audio and visual information should be provided during the journey.

It should be noted that some of these suggestions contradict the current trends in the design of railway carriages, for example, air conditioning which requires the windows to be sealed to function efficiently, and centralised locking of doors for safety reasons. However, some of the other suggestions would benefit all passengers including those with other mental impairments.

#### **4.7 Metro**

A metro is a form of high capacity railway system that serves a large urban area usually with a large proportion running in tunnels and at relatively high frequency. A good example is the London Underground. Table 23 shows the main reasons for not using the Underground by people with mental impairments. Because the system serves London, it is not available to

many people. Anxiety/lack of confidence is the second reason for those with memory, mental health and behavioural impairments and third for those with learning and intellectual impairments. Cost and overcrowding affect more people with mental impairments other than those with intellectual impairments than those with no impairment.

Table 23 Main reasons for not using the Underground as much as desired by people with mental impairments<sup>144</sup>

Rank	Type of impairment					
	None	Learning	Intellectual	Memory	Mental health	Behavioural
1	Transport unavailable 22	Transport unavailable 27	Transport unavailable 12	Transport unavailable 42	Transport unavailable 48	Transport unavailable 26
2	Cost 2	Cost 5	Cost 2	Anxiety/lack of confidence 10	Anxiety/lack of confidence 16	Anxiety/lack of confidence 12
3	Over-crowding 2	Anxiety/lack of confidence 4	Anxiety/lack of confidence 2	Cost 6	Cost 10	Cost 6
4	Anxiety/lack of confidence 1	Over-crowding 3	Over-crowding 2	Over-crowding 6	Over-crowding 7	Over-crowding 6
5	Fear of crime 1	Fear of crime 2	Caring responsibilities; Difficulty getting from stop or station to destination; Lack of help or assistance 1	Difficulty getting in or out of the transport 5	Fear of crime 4	Difficulty getting to stop or station 2

Note: See notes under Table 11.

The difficulties of using the Underground are illustrated in a blog by Claire Lindsay<sup>145</sup> who has autism. She says that when there are diversions, journey restrictions or cancellations, it does not just irritate her, it can feel like the end of the world. One reason she uses the Underground is that she is too scared to use night buses because of how fast they go. She is unable to stand on moving things such as escalators and lifts without being supported, because of dizziness and disorientation. It may take up to twenty visits to a station before she can use it. She starts from just going to see the outside of the station to then walking inside, then another visit to go onto the platform. Even after all that, she might still not be able to continue because they

<sup>144</sup> Source: see note 89.

<sup>145</sup> Lindsay C, **Using the Tube as an autistic person**, a blog on the Transport for All website, available from <http://www.transportforall.org.uk/blog/using-the-tube-as-an-autistic-person>.

might have turned an escalator off or there are too many people on that day, in which case she will end up terminating the journey and going home. Many stations that are accessible to wheelchair users are inaccessible to her because of her autism. She regards Help Points on Tube stations as a brilliant idea but because many of them are down at platform level, she would need to use a lift or a steep escalator to get there, both of which she needs help to do. She finds some railway stations very difficult to navigate because of the information provided: too much information causes confusion and can be overwhelming; too little information causes panic and anxiety. Live announcements are often too loud, too quiet or undecipherable and so she prefers pre-recorded ones. Announcements which are loud may cause disorientation, causing her to freeze on the spot which can annoy other passengers who may react by becoming angry and pushing her.

#### **4.8 Taxi**

Taxis can be very suitable for some people with mental impairments because they can take the traveller from door to door and the driver can provide assistance providing he or she has awareness of the needs of people with mental impairments. Alternatively, the traveller need not communicate directly with the driver if they prefer that, providing that someone else has made the booking and liaises with the driver at the origin.

In its work in the West Midlands, SYSTRA<sup>146</sup> found that focus group participants with learning disabilities used taxis infrequently but were more likely to use them at night because they feel safe using them, unlike the buses.

The reasons why people with mental impairments use taxis less than they wish to are shown in Table 24, which shows that cost is the main reason, which is also true of those with no impairment deterring 61% of those with mental health conditions and 47% of those with memory impairments compared with 16% of those with no impairment. Anxiety/lack of confidence is the second reason cited by people with mental impairments.

#### **4.9 Car**

Because the car offers the opportunity to travel from door to door without interacting with other people, travelling as a car passenger means that many people with mental impairments can travel to the various activities they need to go to, such as hospital appointments. As discussed below, some people with mental impairments drive cars, but as indicated in Table 9 above, fewer people with mental impairments travel by private motor vehicle than the rest of the population. Table 25 shows the reasons for this. It can be seen that for those without a mental impairment, 'cost' is the main reason, followed by 'other reasons'. After that come 'too busy or not enough time', 'vehicle not available when needed', 'parking problems' and then 'caring responsibilities'. For people with mental impairments the reasons are fairly similar. The main differences are that 'difficulty getting in/out of vehicle' appears on the lists of reasons and the fact that 'costs' affect many more of the people in all cases except for

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<sup>146</sup> See note 97.

those with intellectual impairments than those with no impairment. ‘Other reasons’ may well include the inability to drive because of their impairment.

Table 24 Main reasons for not using taxi or minicab as much as desired by people with mental impairments<sup>147</sup>

Rank	Type of impairment					
	None	Learning	Intellectual	Memory	Mental health	Behavioural
1	Cost 16	Cost 32	Cost 10	Cost 47	Cost 61	Cost 27
2	Transport unavailable 1	Anxiety/lack of confidence 2	Anxiety/lack of confidence 2	Anxiety/lack of confidence 7	Anxiety/lack of confidence 9	Anxiety/lack of confidence 7
3	Other reasons 1	Fear of crime 1	Transport unavailable 1	Difficulty getting in or out of the transport 3	Difficulty getting in or out of the transport 2	Lack of help or assistance 2
4		Difficulty getting in or out of the transport 1	Fear of crime 1	Other reasons 2	Other reasons 2	Difficulty getting to stop or station 1
5		Other reasons 1	Difficulty getting in or out of the transport 1	Attitudes of staff; Lack of help or assistance 1	Lack of help or assistance; Transport unavailable; Caring responsibilities 1	Transport unavailable 1

Note: See notes under Table 11.

As discussed above, a mental impairment may affect the ability to comprehend and recall information and process it in order to take decisions while travelling. On most modes of travel, difficulties assimilating information, processing it and then using it to take decisions may be challenging to the person concerned and possibly stressful, but there is not likely to be a significant impact on others. However, driving a car is a different matter, because the inability to take the correct decision at the correct time can lead to injuries and fatalities to others as well as the person concerned.

<sup>147</sup> Source: see note 89.

Table 25 Main reasons for not using a private motor vehicle as much as desired by people with mental impairments<sup>148</sup>

Rank	Type of impairment					
	None	Learning	Intellectual	Memory	Mental health	Behavioural
1	Cost 9	Cost 18	Other reasons 4	Cost 28	Cost 36	Cost 15
2	Other reasons 5	Other reasons 6	Cost 4	Other reasons 10	Other reasons 13	Other reasons 7
3	Too busy or not enough time 3	Too busy or not enough time 4	Parking problems 3	Parking problems 8	Difficulty getting in/out of vehicle 9	Vehicle not available when needed 5
4	Vehicle not available when needed 2	Parking problems 4	Vehicle not available when needed 2	Difficulty getting in/out of vehicle 8	Vehicle not available when needed 8	Difficulty getting in/out of vehicle 5
5	Parking problems 2	Vehicle not available when needed; Difficulty getting in/out of vehicle 3	Difficulty getting in/out of vehicle; Lack of help or assistance 2	Vehicle not available when needed 6	Parking problems 7	Parking problems 3

Note: See notes under Table 11.

In Britain, as in other countries, it is necessary to pass a driving test in order to be able to drive a car without supervision. In Britain, driving licences are issued by the Driver and Vehicle Licensing Agency (DVLA) which issues guidance<sup>149</sup> on the fitness to drive of people with various impairments and health conditions. It lists the following elements of safe driving:

- Vision;
- Visuospatial perception;
- Hearing;
- Attention and concentration;
- Memory;
- Insight and understanding;
- Judgement;
- Adaptive strategies;

<sup>148</sup> Source: see note 89.

<sup>149</sup> Driver and Vehicle Licensing Agency, **Assessing Fitness to Drive – a guide for medical professionals** (2016), available from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/526635/assessing-fitness-to-drive-a-guide-for-medical-professionals.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/526635/assessing-fitness-to-drive-a-guide-for-medical-professionals.pdf).

- Good reaction time;
- Planning and organisation;
- Ability to self-monitor;
- Sensation;
- Muscle power and control;
- Coordination.

Most of these could be affected adversely by a mental impairment. The action required by a person with a mental impairment who wishes to obtain a driving licence is indicated in Table 26. It can be seen that there are three levels of reporting the mental impairment:

- An absolute requirement to inform the DVLA if the person has a particular condition, such as dementia or bipolar disorder;
- A requirement to inform the DVLA if the condition affects the ability to drive safely, for example anxiety or autism;
- A requirement to inform the DVLA, if their doctor advises that it affects the person's ability to drive safely, for example for ADHD or obsessive compulsive disorder.

It is possible, under some circumstances, to regain a driving licence that has been revoked.

Many mental impairments have varying degrees of severity, and so being diagnosed with one does not necessarily mean that the person concerned is not allowed to hold a driving licence: for some conditions a doctor or other relevant healthcare professional would need to make the judgement as to whether a person with a mental impairment is fit to drive. This is particularly relevant in the case of progressive conditions such as dementia, where the transition from being fit to drive to not being requires careful judgement. This is discussed below. This is a very sensitive issue because a person who has been able to drive for many years who is told that they may no longer do so, faces a huge change in their level of independence, with consequences not only for their whole way of life, but also that of their family who may have to become responsible for escorting the person, ensuring that he or she can obtain food and other necessities, assisting them to maintain their social contacts and helping them to adjust mentally to their increased dependency on others.

The effects of driving cessation on the lives of elderly people with dementia and their carers has been explored in a survey<sup>150</sup> carried out in California in which questionnaires were sent to all 922 residents whose driving licences had been revoked or suspended due to dementia or suspected dementia in 1995-96. After invalid responses and those under the age of 65 had been eliminated, 315 responses remained. The researchers examined changes in trip patterns and found increased dependence on other household members and friends to give lifts. Some carers reported missing work sometimes to provide transport, with some having to give up

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<sup>150</sup> Taylor B D and Tripodes S, The effects of driving cessation on the elderly with and their caregivers, **Accident Analysis and Prevention**, **33** (2001), 519 – 528, available from [http://ac.els-cdn.com/S0001457500000658/1-s2.0-S0001457500000658-main.pdf?\\_tid=ca52c4da-1420-11e5-9ce4-00000aacb362&acdnat=1434456857\\_c51a3455824f9e0598c130d0a02ddaef](http://ac.els-cdn.com/S0001457500000658/1-s2.0-S0001457500000658-main.pdf?_tid=ca52c4da-1420-11e5-9ce4-00000aacb362&acdnat=1434456857_c51a3455824f9e0598c130d0a02ddaef).

Table 26 The requirements to inform the DVLA about mental impairments for driving licence purposes<sup>151</sup>

Condition	Type of mental impairment	The DVLA must be informed	The DVLA must be informed if the condition affects the ability to drive safely	The DVLA needs to be informed if a doctor advises that the condition affects the ability to drive	The DVLA need not be informed.
Cerebral palsy	Learning	X			
Dyslexia	Learning				X
Learning difficulties	Learning	X			
Dementia	Intellectual	X			
Traumatic brain injury	Intellectual	X			
Severe memory problems	Memory	X			
Agoraphobia	Mental health		X		
Anxiety	Mental health		X		
Bipolar disorder	Mental health	X			
Depression	Mental health			X	
Obsessive compulsive disorder	Mental health			X	
Psychosis	Mental health	X			
Psychotic depression	Mental health	X			
Schizo-affective disorder	Mental health	X			
Schizophrenia	Mental health	X			
Asperger syndrome	Behavioural		X		
Attention deficit hyperactivity disorder (ADHD)	Behavioural			X	
Autistic spectrum disorders (ASD)	Behavioural		X		
Tourette's syndrome	Behavioural			X	

work altogether to provide chauffeuring services. Examples of the effects of losing access to a car are given in a New Zealand study<sup>152</sup> in which interviews were carried out with 28 couples and 43 single people with an average age of 84.5 for men and 81.4 for women who had all

<sup>151</sup> GOV.UK, **Check if you need to tell DVLA about a health condition**, available from <https://www.gov.uk/health-conditions-and-driving>.

<sup>152</sup> Davey J A, Older people and transport: coping without a car, **Ageing and Society**, 27 (2007), 49–65.

been without private transport for at least six months, but had not necessarily been diagnosed as having a mental impairment. They coped in various ways, with the 'serious' transport requirements often being provided by alternative means, but many of the discretionary trips that contribute to the quality of life being lost. Other problems included not being able to get to special occasions such as funerals and reunions, the unreliability of taxis which do not turn up, erratic bus services, missed opportunities such as access to sales in the shops, fresh fruit and vegetables, and the opportunity to shop at a leisurely pace and make comparisons. For some of them, visits to friends and relations were replaced by being visited by them. Some people had home deliveries from supermarkets or by friends and relatives and bought clothes from catalogues. This means that at least some of their needs were met, but they missed the social contact and stimulation of leaving home and the physical activity.

As mentioned above, progressive conditions such as dementia, are particularly difficult when it comes to determining whether or not someone should drive. According to the Alzheimer's Society<sup>153</sup> most people stop driving within three years after the first signs of the disease. In Britain, anyone who is unsure about their ability to drive can go to a mobility centre for an assessment. Once a person has been diagnosed with dementia they must inform the DVLA immediately who will send the person a questionnaire that seeks the person's permission to obtain medical reports from their GP or specialists. Having seen the reports, DVLA will decide whether the person can continue to drive. For people with dementia, the DVLA<sup>154</sup> says that having poor short-term memory, being disoriented and showing lack of insight and judgement almost certainly mean the person is not fit to drive. The person may be asked to take a driving assessment. If they are allowed to continue driving, their condition is reviewed annually. If a person diagnosed with dementia does not inform DVLA about their diagnosis they can be fined up to £1000 and if they continue to drive against advice from their doctor, the doctor may inform DVLA if he or she feels the person is not safe to drive. If the DVLA decides that they can continue driving, it will issue a new driving licence, usually for one year, but can be for up to three years. If DVLA decides a person may not drive he or she can appeal in a magistrate's court (and not drive in the meantime).

Whilst this procedure seems fairly straightforward, difficulties can arise in a number of stages of the process. Firstly, in order to be diagnosed with dementia, the person concerned has to talk to medical professionals about their condition, and that requires acknowledgement of the fact that they are having difficulties, and because the condition is progressive, he or she may be driving with mild dementia without realising it. Members of their family may be aware that the person is starting to have difficulties with memory, comprehension and decision making, but be reluctant to acknowledge to the person, or even to themselves, that he or she

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<sup>153</sup> Alzheimer's Society, Driving and dementia factsheet (2013), available from [http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1780](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1780).

<sup>154</sup> See note 149.

has dementia. O'Neil<sup>155</sup> argues that geriatricians nowadays have a better understanding of the balance between mobility and safety. He also argues that clinical assessments of the ability to drive often concentrate on issues at the operational level such as the reaction time to a hazardous situation whereas, in fact, the shortest reaction time is in the 15-25 year age group, which is the group with the highest likelihood of having a crash. He argues that it would be better to consider decisions at the strategic and tactical levels such as when and where to drive, and so clinicians should be looking for evidence of inappropriate planning of trips or driving when another mode would be more appropriate. He acknowledges that an on-road test is generally seen as the best way to assess driving ability in an elderly driver, testing his or her response to road signals, positioning on the road and awareness of other road users amongst other things, but there are some difficulties with this: firstly, some people with dementia may perform at an acceptable level on a road test but not be safe to drive, secondly, the limited availability of suitable test centres, and thirdly the cost of being assessed. There are only 16 mobility centres in Britain<sup>156</sup> which means that many people may not live near to one. The cost of being assessed may deter some people from referring themselves to such centres.

The practical difficulties of obtaining an assessment raises the question of whether there are other effective methods that can be used to determine suitability for driving. One way to do this is to establish a correlation between an office or clinic-based assessment system and a road test. One approach to assessing the ability of people with dementia continuing to drive is the 4Cs approach according to O'Connor and colleagues<sup>157</sup>. This involves evaluating the effectiveness of the 4Cs of crash history in the past two years, concern based on a family report, clinical status, that is medical diagnosis associated with driving risk, and cognition based on the family report and clinical impressions obtained from interview questions focused on memory complaints, lapses in judgment, and problems with daily activities. They examined a sample of 160 people with dementia who all underwent a 45-minute road test modelled on the Washington University Road Test<sup>158</sup>. The 160 participants were all the people out of 288 who had complete driving assessment records during the period 2003-2009 at the Beth Israel Deaconess Medical Center in Boston in the USA. Performance on the road test resulted in three possible outcomes: pass, marginal outcome, or failure. Fifty participants (31%) were considered safe to drive, 43 (27%) were considered marginal drivers and were referred for remediation and re-evaluation, and 67 (42%) were not considered safe to

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<sup>155</sup> O'Neill D, Deciding on driving cessation and transport planning in older drivers with dementia, **European Geriatric Medicine**, 1 (2010), 22-25, available from <http://www.em-consulte.com/showarticlefile/245663/main.pdf>.

<sup>156</sup> Driving Mobility, **About us**, available from <http://www.drivingmobility.org.uk/>.

<sup>157</sup> O'Connor M G, Kapust L R, Lin B, Hollis A M and Jones R N, The 4Cs (crash history, family concerns, clinical condition, and cognitive functions): a screening tool for the evaluation of the at-risk driver, **Journal of the American Geriatrics Society**, 58 (2010), 1104-8., available from <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2010.02855.x/pdf>.

<sup>158</sup> Carr D B, Barco P P, Wallendorf M J, Snellgrove C A and Ott B R, Predicting road test performance in drivers with dementia, **Journal of the American Geriatrics Society**, 59 (2011), 2112-2117, available from <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03657.x/pdf>.

continue driving. The domains most strongly associated with the road test outcome were cognitive function and family concerns. In another American study<sup>159</sup> 40 drivers with probable early Alzheimer's disease were compared with 115 elderly drivers without neurological disease by giving them a battery of cognitive, visual and motor tests and getting them to drive a standardised 35 mile route in an instrumented vehicle in urban and rural settings. The 40 drivers with probable early Alzheimer's were recruited from the records of the Department of Neurology at the University of Iowa after eliminating all those who did not meet the selection criteria. The control sample was recruited from local volunteers. The participants were videoed as they drove and their driving performance assessed by driving experts. The drivers with Alzheimer's committed significantly more safety errors than those without. The most common errors were lane violations. The number of errors increased with age. A composite score based on eight neuropsychological tests was a significant predictor of safety errors in subjects with Alzheimer's. They concluded that these tests can be used to predict whether a patient with Alzheimer's can drive safely.

There are different views on whether drivers in the early stages of dementia should be allowed to drive. For example, Eby and colleagues carried out a study<sup>160</sup> of drivers in the early stages of dementia using in-vehicle technology (four cameras, plus radar to measure speed and distances to other vehicles, accelerometer and a yaw sensor) in Michigan in the USA. They compared a convenience sample of 17 drivers with early-stage dementia with 26 older drivers without dementia. Those with dementia were found to have significantly restricted driving space (that is, they drove less, travelled less on the freeway, drove to about half as many unique destinations per week, and stayed significantly closer to home). They also drove less at night. They were more likely to travel slower than the surrounding traffic and less likely to follow other cars too closely. They were also less likely to use a seat belt. They made few wayfinding errors but were more likely to get lost. However, these factors do not directly impinge on safety, and the researchers concluded that they drove as safely as the comparison group.

Similarly, Drachman and colleagues<sup>161</sup> used a questionnaire-based study to determine the risk of car crashes among Alzheimer's disease patients who continued to drive after the onset of Alzheimer's, compared with normal age-matched control subjects and other drivers' statistical records. They provided a brief questionnaire to the caregivers of 130 Alzheimer's patients and to 112 age-matched, non-demented control subjects and their spouses. Annual rates of occurrence and severity of all crashes, and of crashes reported to the authorities,

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<sup>159</sup> Dawson J D, Anderson S W, Uc E Y, Dastrup E and Rizzo M, Predictors of driving safety in early Alzheimer disease, **Neurology**, **72** (2009), 521–527, available from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2677513/pdf/6274.pdf>.

<sup>160</sup> Eby D W, Silverstein N M, Molnar L J, LeBlanc D and Adler G, Driving behaviors in early stage dementia: a study using in-vehicle technology, **Accident Analysis and Prevention**, **49** (2012), 330-337, available from <http://www.sciencedirect.com/science/article/pii/S0001457511003265>.

<sup>161</sup> Drachman D A, Swearer JM, the Collaborative Study Group, Driving and Alzheimer's disease: the risk of crashes, **Neurology**, **43** (1993), 2448-2456.

were determined from the responses of spouses and other carers. They concluded that the existing evidence suggests that Alzheimer's patients who drive present a slightly increased risk for crashes compared with drivers of all ages but a lower risk than young unimpaired drivers, especially males. They took the view that during the first 2 to 3 years after the onset of Alzheimer's, the magnitude of risk of crashes is well within the accepted risk for other registered drivers.

A different view was taken by Friedland and colleagues<sup>162</sup> who assessed the occurrence and related features of motor vehicle crashes in patients with Alzheimer's disease by studying 30 patients who had been followed longitudinally and 20 healthy age-matched control subjects in Bethesda in Maryland in the USA. The participants with Alzheimer's were recruited from the community through local doctors and community organizations while the control sample were recruited through advertisements and a volunteer bureau. Data were gathered from first-degree relatives who had lived with the subjects for the previous 5 years or more. Forty-seven percent of the patients with Alzheimer's incurred at least one crash while they were driving, whereas only 10% of the control subjects had had a crash in the previous 5 years. They recommend that patients with the diagnosis of dementia of the Alzheimer's type should not drive a motor vehicle. They argue that there is no initial period after the onset of the disease when driving is safe and that family members cannot be relied upon to predict the safety of continued driving.

This raises the issue of the initial identification that driving may be a problem for people with dementia. In many cases this will be a by spouse or carer. Brown and colleagues<sup>163</sup> carried out a study of 75 older people (17 with mild Alzheimer's disease, 33 with very mild Alzheimer's and 25 controls) in Rhode Island in the USA. The 50 people with Alzheimer's were all enrolled in a longitudinal study of driving and dementia and the control sample were all family members of dementia patients with no history of dementia. The participant, an informant such as a spouse or carer, and a neurologist rated the participants' driving abilities on a 3-point scale (safe, marginal, unsafe) which were compared with the assessment of a professional driving instructor using a 108-point on-road driving assessment and then rated driving ability on the 3-point scale. Only the neurologist's rating of the participants' driving abilities was significantly related to the on-road driving score. They were also the most stringent, followed by the informant and then the participant. This suggests that doctors need to be involved in the process, and that if the spouse or carer of the person concerned has any doubts about his or her driving ability, they should consult a doctor immediately so that advice can be obtained.

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<sup>162</sup> Friedland R P, Koss E, Kumar A, Gaine S, Metzler D, Haxby J V and Moore A, Motor vehicle crashes in dementia of the Alzheimer type, **Annals of Neurology**, **24** (1988), 782–786, available from <http://onlinelibrary.wiley.com/doi/10.1002/ana.410240613/pdf>.

<sup>163</sup> Brown L B, Ott B R, Papandonatos G D, Sui Y, Ready, R E and Morris J C, Prediction of On-Road Driving Performance in Patients with Early Alzheimer's Disease, **Journal of the American Geriatrics Society**, **53** (2005), 94–98, available from <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2005.53017.x/pdf>.

Mild cognitive impairment (MCI) can lead to dementia. People with MCI which does not impair their driving, may drive and need not inform the DVLA<sup>164</sup>. If their driving is impaired they must not drive, and must inform the DVLA who will make medical enquiries.

Wadley and colleagues<sup>165</sup> compared 46 participants with MCI with 59 controls on a driving evaluation conducted by a driving rehabilitation specialist. Potential participants were recruited through clinical cases presenting to University of Alabama at Birmingham Memory Disorders Clinic and through community talks and health fairs. Those with MCI showed significantly lower performance than the controls on ratings of their abilities to manoeuvre the car, but their performance was no worse than some people in the control group. The overall differences were fairly small. They concluded that the increased incidence of dementia amongst those with MCI and the known impact of dementia on driving suggests that there is a need for increased vigilance by doctors, family members and individuals with MCI.

People with traumatic brain injury must not drive and must notify the DVLA<sup>166</sup>. They may be considered being allowed a licence, usually after 6 to 12 months dependent on features such as seizures and post-traumatic amnesia. There will need to have been satisfactory clinical recovery and in particular no visual field defects or cognitive impairment likely to affect safe driving.

Because a learning disability is acquired before, during or shortly after birth the situation is different from that for people with an intellectual impairment that is acquired later in life. People with a learning disability which the DVLA<sup>167</sup> defines as having significantly below average general intellectual functioning, accompanied by severe limitations in adaptive functioning in at least two out of nine areas such as communication and self-care, must inform the agency about their condition. If their condition is severe they are not allowed to drive, but may be allowed to if their condition is mild. In the latter case, the DVLA may require an assessment of adequate functional ability at the wheel.

In Sweden, Falkmer<sup>168</sup> found that the total duration of the driving tuition given by a driving instructor was found to be almost nine times higher for learner drivers with cerebral palsy than for non-disabled learner drivers. He reports that visual search structures for learner drivers with cerebral palsy were found to be less flexible than other learner drivers.

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<sup>164</sup> See note 149.

<sup>165</sup> Wadley V G, Okonkwo O, Crowe M, Vance D E, Elgin J M, Ball K K and Owsley C, Mild cognitive impairment and everyday function: an investigation of driving performance, **Journal of Geriatric Psychiatry and Neurology**, **22** (2009), 87-94, available from <http://jgp.sagepub.com/content/22/2/87.full.pdf+html>.

<sup>166</sup> See note 149.

<sup>167</sup> See note 149.

<sup>168</sup> Falkmer T, Transport mobility for children and adolescents with cerebral palsy (CP) **Scandinavian Journal of Occupational Therapy**, **8** (2001), 158, available from <http://informahealthcare.com/doi/pdf/10.1080/110381201750464520>.

It is not necessary to report being dyslexic to the DVLA. In their focus groups to establish the travel issues for people with dyslexia, Lamont and colleagues<sup>169</sup> identified the following difficulties when driving with dyslexia:

- Text-based directions, for example in web-based journey planners, may be difficult to use if there are lengthy lines of text which are too difficult to process;
- Road maps may be difficult to use because of the choice of colour or fonts and the large amount of information;
- Road signs, particularly if there is a large amount of information on a single sign or multiple signs, for example at a road junction.

Satellite navigation systems can offer ways to address these issues, and may be regarded as essential aids to driving by some people with dyslexia.

For people with mental health issues, the Driver and Vehicle Licensing Agency says<sup>170</sup> that people with mild to moderate anxiety or depression without significant memory or concentration problems, agitation, behavioural disturbance or suicidal thoughts may drive and need not notify the DVLA. People with severe anxiety or depression must not drive and must notify the DVLA. People with other severe mental health conditions must not drive and must notify the DVLA. They may be issued with a driving licence under certain conditions such as remaining well and stable for at least 3 months and adhering adequately to any agreed treatment plan. Mind explains<sup>171</sup> the rights that people with mental health problems have to drive, what information they need to tell the DVLA and how to appeal if their driving licence is taken away.

The experience of driving by a person with a mental health condition is illustrated in the blog by Joanne<sup>172</sup>. She suffers from anxiety and so does not drive because her anxiety plus her OCD (Obsessive compulsive disorder) means that she is too concerned about killing someone to drive a car. She used to drive but her anxiety made her drive very slowly and hesitantly, and when she was not driving, she would think about all the moments when she could have killed someone. Her inability to drive has meant that she has become very dependent on others to give lifts to her son so that he can attend after school activities which she cannot reciprocate. Her anxieties prevented her from crossing the road in the past but she received help to address this issue and can now do so.

People with disorders such as attention deficit hyperactivity disorder (ADHD), Asperger's syndrome, autism spectrum disorders (ASD) and severe communication disorders may be allowed to drive. The Driver and Vehicle Licensing Agency<sup>173</sup> considers factors such the level

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<sup>169</sup> See note 67.

<sup>170</sup> See note 149.

<sup>171</sup> Mind, **Fitness to drive**, available from <http://www.mind.org.uk/information-support/legal-rights/fitness-to-drive/medication/>.

<sup>172</sup> Time to Change, **So, why don't you drive then?** Joanne's blog, 9 February 2012, available from <http://www.time-to-change.org.uk/blog/so-why-dont-you-drive-then>.

<sup>173</sup> See note 148.

of impulsivity and the awareness of the impacts of behaviour on the person concerned and others.

There is a lack of high quality studies on the mechanism underlying driving performance outcomes in teenagers with ADHD and ASD according to the literature review by Classen and Monahan<sup>174</sup>.

In their surveys of people with ASD in New Jersey in the United States, Feeley and colleagues<sup>175</sup> found that the following were the most commonly cited difficulties by the participants with ASD, many of whom drove:

- Judging the speed of traffic and/or distance of other travelling cars;
- Determining how to adjust appropriately to speed limit changes;
- Maintaining attention;
- Following directions and/or reading maps;
- Anticipating the actions of other drivers;
- Reacting quickly to roadway situations;
- Understanding various roadway signage and driving environments.

Of the 703 adults with ASD in the survey, 47 had a driving licence. Of the 47, 61% said that they have some difficulty when driving. 55% said they had difficulty dealing with traffic, 34% mentioned difficulty due to distractions near roads, 28% mentioned difficulty judging distance, and another 28% mentioned difficulty with parking. Due to these difficulties, 26% did not drive not at all. Some of them had difficulties when being driven by others, including anxiety, displaying aggression, displaying agitation and compulsive behaviour.

Transporting children with autism as passengers in cars may pose certain risks. For example, Yonkman and colleagues<sup>176</sup> examined reports about 82 children with ASD conducted by paediatric occupational therapists at an outpatient centre of a large children's hospital in the USA. This revealed that 74% of the children with ASD were escaping their child safety restraint. More than 20% of parents reported that their child demonstrated aggressive or self-injurious behaviour during travel, affecting not only their own safety but also that of others in the vehicle, including the driver. The paper does not report equivalent figures for children without ASD, but the figures are likely to be lower.

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<sup>174</sup> Classen S and Monahan M, Evidence-based review on interventions and determinants of driving performance in teens with attention deficit hyperactivity disorder or autism spectrum disorder, **Traffic Injury Prevention**, **14** (2013), 188-193, available from <http://www.tandfonline.com/doi/abs/10.1080/15389588.2012.700747#.VMtPbdhLdhc>.

<sup>175</sup> See note 80.

<sup>176</sup> Yonkman J, Lawler B, Talty J, O'Neil J and Bull M, Safely transporting children with autism spectrum disorder: evaluation and intervention, **American Journal of Occupational Therapy**, **67** (2013), 711-716, available from <http://search.proquest.com/docview/1465127384/fulltextPDF?accountid=14511>.

#### 4.10 Conclusions on travel by people with mental impairments

This section of the report has identified a number of barriers to travel for people with mental impairments. The main reason seem to be anxiety and lack of confidence. This implies that people need reassurance when they travel to help them overcome their anxiety and to give them greater confidence. On public transport, overcrowding can be an issue and some people with mental impairments are concerned about the behaviour of other passengers. Another issue can be difficulty interacting with staff, particularly bus drivers, some of whom behave badly towards people with mental impairments. These are all issues that may be overcome if the person concerned can acquire the confidence to deal with other people. As discussed in Section 2, confidence also can come from having the ability to obtain sufficient information both before travelling and during the journey, being able to process it effectively to make decisions at appropriate points in the journey and the ability to cope if difficulties arise, either because of a failure in the transport system or if the person becomes lost. This implies having information presented in a format that can be comprehended by the traveller, both at the trip planning stage and during the journey. The former may be in printed form, the internet, from a phone call or from another person such as a carer. During the journey, the information may come from various sources including people, signs or mobile devices.

Another issue for using public transport is the ability to travel from home to the bus stop or railway station and from the stop or station to the final destination, which will usually be by walking. This involves the ability to navigate which requires clear information in the form of signs or from a mobile device and a legible landscape with clear landmarks.

Cost can deter many people from travelling, but as the tables in the previous section showed, more people with mental impairments are deterred from travel because of cost than the general public. This is partly because fewer disabled people are employed than non-disabled<sup>177</sup> and so, on average, incomes are lower.

The public health benefits of increased mobility are increasingly being recognised, and those currently experiencing low levels of mobility, such as people with mental impairments, could have the most to benefit from improved mobility in relation to their physical and mental wellbeing.

It should be acknowledged that the evidence presented in this section does not explicitly cover the barriers to travel by each mode for each individual type of mental impairment, but the evidence does cover the main land-based modes of travel and examples of the various types of impairment. Whilst the evidence usually refers to particular types of impairment, some of the barriers such as lack of confidence and cost can probably apply to the whole population to some extent under some circumstances; the evidence suggests that, in some cases, they apply more to people with mental impairments. At a more detailed level, they will

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<sup>177</sup> Office for Disability Issues, **Disability Facts and Figures** (2014), available from <https://www.gov.uk/government/statistics/disability-facts-and-figures>.

apply more to people with some mental impairments than others. It should be remembered that everybody with a mental impairment is different and some people may have more than one impairment. Nonetheless the general picture of the key barriers to travel are fairly clear.

Some of the differences between the barriers that affect people with various impairments, and possible ways of overcoming them reflect the nature of the impairment. Learning and behavioural impairments are acquired at or near birth, and so people go through childhood with them, and will have them all their lives, but the conditions do not worsen, in general. Intellectual impairments are acquired during life, often in later life, such as dementia, and often lead to a gradual loss of the faculties. Some mental health conditions are acquired at some point in life and may cease after a period of time. Other mental health conditions may fluctuate over time, as shown by the fact that many people with mental health issues do not buy a rail ticket in advance because they do not know whether they will feel able to travel on the day.

The differences between the various types of impairment are illustrated by the conditions for obtaining a driving licence as discussed in Section 4.9. People with severe learning impairment are unlikely to be able to obtain a driving licence while people with a deteriorating condition such as dementia will probably have to give up their driving licence about three years after the initial diagnosis. Some people with mental health conditions may have to give up driving for a period, but are, following an assessment, allowed to resume driving.

Whilst most improvements in the provision of travel facilities will benefit people with different types of impairment to a greater or lesser extent, such as bus drivers learning how to behave towards people with hidden disabilities, there are a few situations where there could be conflicts. The provision of information is important, and because different people have different needs, it may be necessary in some situations, to provide it in different formats. However some people with autism and people with dyslexia may find having lots of information confusing. In other cases there may be conflicts with other objectives such as increasing safety on trains by having doors operated electronically by the driver which cannot be opened manually by passengers, which may cause distress to some people with agoraphobia. These types of issues will need considerable thought, but appropriate solutions can probably be found in many cases.

Summing up, the key needs seem to be:

- Developing ways of increasing confidence and providing reassurance before and during journeys including:
  - The provision of clear information in appropriate formats so that it can be comprehended by people with mental impairments;
  - Simplification of journeys, so that decision making is easier;
  - Easier communication with people on the journey;
  - Greater understanding and empathy from staff and fellow passengers;

- Providing cheaper travel in recognition of the fact that many people with mental impairments have low incomes, and, in some cases, a need to make journeys such as to medical facilities, and that, for some people, travel provides benefits in terms of contact with others.

Ways of addressing these issues will be discussed in the next section.

## 5 Interventions to reduce the barriers to travel for people with mental impairments

### 5.1 The nature of interventions

In the previous section, some of the barriers that hinder travel by people with mental impairments were identified. These barriers require mental skills of the type discussed in Section 2 of this report to overcome them. Having one or more mental impairment may prevent some people from using those skills fully. Having examined the barriers to travel it is possible to identify some ways in which mental skills can be enhanced, as indicated in Table 27. It can be seen that the key to enhancing travel skills is through providing training and familiarisation in preparation for making journeys.

Table 27 Ways in which mental skills used in travelling can be enhanced

<b>Mental skill used in travel</b>	<b>Ways in which these skills can be enhanced</b>
Ability to remember	<ul style="list-style-type: none"> <li>• Provide training to remember key points in a journey</li> <li>• Providing memory aids such as written or electronic information</li> </ul>
Comprehension	<ul style="list-style-type: none"> <li>• Provide training in the relevant skills to understand, for example, road signs</li> </ul>
Decision making	<ul style="list-style-type: none"> <li>• Provide training in decision making at critical points in journeys such as crossing the road and identifying the correct bus</li> </ul>
Interpersonal communication	<ul style="list-style-type: none"> <li>• Give training in the type of person to approach for help or assistance</li> </ul>
Confidence in travelling alone	<ul style="list-style-type: none"> <li>• Use practice to build up familiarity, for example, with the route or vehicle, and knowledge from about where to go for assistance</li> </ul>
Ability to behave appropriately	<ul style="list-style-type: none"> <li>• Provide training in coping strategies</li> </ul>

The alternative to enhancing the skills of the individual, is to modify the environment, as implied in the social model of disability. Examples of ways in which this can be done are shown in Table 28. A wide range of options are available to modify the travel environment. Many of these relate to providing information in suitable formats clearly at appropriate points during the journey. Others relate to training staff to understand the needs of people with mental impairments and educating the public to be more empathetic.

Various interventions have been developed to enhance the travel skills of people of people with mental impairments and modify the travel environment. Some of the interventions re examples of adjustments that can be made by service providers to reduce the disadvantage that a disabled person has, as required under the Equality Act 2010, as discussed in Section 1.

Table 28 Modifications to the travel environment to reduce the need for skills used in travelling

<b>Mental skill used in travel</b>	<b>Ways in which the travel environment can be modified to reduce the need for these skills</b>
Ability to remember	<ul style="list-style-type: none"> <li>• Provide information frequently during the journey</li> <li>• Provide clear, accurate information at decision points</li> <li>• Make travel information more memorable</li> </ul>
Comprehension	<ul style="list-style-type: none"> <li>• Make travel information simpler</li> <li>• Provide information in various ways: written, pictorial, audible, etc.</li> <li>• Remove irrelevant information at decision points</li> </ul>
Decision making	<ul style="list-style-type: none"> <li>• Make decision points in journeys clearer</li> <li>• Provide appropriate, clear information for each alternative at decision points</li> </ul>
Interpersonal communication	<ul style="list-style-type: none"> <li>• Give staff training to provide information in appropriate ways</li> <li>• Educate the public to have greater empathy with people with mental impairments</li> </ul>
Confidence in travelling alone	<ul style="list-style-type: none"> <li>• Provide clearer information</li> <li>• Improve the environment to reduce aspects that negatively affect the confidence to travel such as vandalism and graffiti</li> <li>• Provide more staff</li> <li>• Provide clearly identifiable places of safety</li> <li>• Provide ways of communication to request assistance</li> </ul>
Ability to behave appropriately	<ul style="list-style-type: none"> <li>• Provide places of safety</li> <li>• Make car parking spaces available near to destinations</li> <li>• Train staff to understand behavioural difficulties</li> <li>• Educate the public to have greater empathy</li> </ul>

The interventions are considered below under six headings: interventions to enhance travel skills, interventions to simplify the journey, interventions to provide clear information, interventions to provide support on the journey, interventions to make travel cheaper and comprehensive packages of measures.

## **5.2 Interventions to enhance travel skills**

### *5.2.1 Travel training*

Travel training provides tailored and practical help in travelling by public transport, on foot or by bicycle. The objective is to help people travel independently with confidence. The term

‘travel training’ is used to refer to a range of comprehensive schemes or programmes and can take various forms. Travel training usually involves classroom exercises and journeys with a trainer on a one-to-one basis to provide experience and to give people with mental impairments and others the confidence to make unaccompanied journeys.

An example of the content in a course has been described by Carmien and colleagues<sup>178</sup> who outlined some of the stages that they observed in travel training for teenagers with cognitive disabilities in the USA to assist them to navigate on public transport:

- Instructors trained the students for activities such as planning, waiting and moving;
- Planning activities were completed in the classroom before travelling, including creating simple maps and schedules, extracting trip information from system maps and timetables, and the connection between timetables and clocks; the researchers observed that some of the students did not have a good understanding of the concept of time;
- As the students moved to and from the bus stops, signs and landmarks were highlighted by the instructors;
- Navigation lessons were interleaved with education in other essential life skills such as social etiquette, which is needed to travel safely on public transport, but it caused problems with focusing on navigational tasks.

Good practice in setting up travel training schemes<sup>179</sup> includes:

- The scheme needs to be clearly targeted towards particular individuals and groups, to be able to cater for specific needs;
- Clear eligibility criteria should be established; funders may wish to stipulate who is eligible;
- Travel training can be most effective when delivered early on (i.e. during childhood) and preceding a transition in the learner’s life (for example, before changing school or workplace);
- In determining the key driver for a scheme, the wider benefits should be considered as this is likely to increase potential sources of funding.

The Department for Transport argues<sup>180</sup> that travel training provides good value for money because in comparison to infrastructure measures, travel training schemes have relatively low costs, with the main costs predominantly relating to staff time. Economies of scale will apply to travel training schemes, because while direct costs are likely to increase proportionally to the number of people receiving training, indirect costs and overheads will not increase at the same rate. Therefore, unless scheme promoters believe that they will be responding to a specific niche sector, they should seek to maximise the number of people receiving training,

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<sup>178</sup> See note 10.

<sup>179</sup> Department for Transport, **Travel Training: Good Practice Guidance** (2011), available from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/4482/guidance.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/4482/guidance.pdf).

<sup>180</sup> See note 179.

whilst demonstrating that indirect costs and overheads have been kept as low as possible. Direct financial savings are possible if training reduces the need for public sector outlay on supported travel associated with trips to and from colleges, schools or social service premises, which could take the form of subsidised public transport services or payment for taxis. There may be savings in mini-bus services through savings in fuel and possibly in the number of minibuses that have to be operated.

An example of the effects of travel training is given in 'Valuing People Now: a new three-year strategy for people with learning disabilities'<sup>181</sup> published by HM Government in 2009: Colin used taxis to get him to his schools and college. After finishing education, he became socially isolated in his village as no funding was available to allow him to access things he wished to do. The only time he went out was when he went with his carers. Two years ago (when he was 27) he was referred for travel training as he had been offered a place at a training centre run by CASE which is an accredited training organisation providing meaningful, effective training and work experience opportunities. Colin commented: *"After having my travel training, I felt a lot more confident and began to catch the bus into Beverley. After my training I began to catch the bus into Hull too. I now come through to Hull every Saturday to meet up with my friends from CASE. We go to the café and look around the shops. It makes me feel proud of what I can do. I think it's a good idea for others to try to learn how to travel independently."*

There have been a number of travel training schemes in Manchester using guidance<sup>182</sup> produced for GMPTTE (Greater Manchester Passenger Transport Executive) by the Halcrow Group Limited based on an email survey of schemes in the UK, and overseas, 40 phone interviews about a range of schemes in the UK, plus 6 in-depth case studies. One of the schemes set up in Greater Manchester was for young people attending secondary schools in Trafford who had Special Educational Needs and qualified for free home to school transport<sup>183</sup>. The skills taught included:

- Road safety;
- How to plan a journey;
- How to access buses and trams;
- Learning routes and landmarks;
- What to do in an emergency.

GMPTTE estimated that a child would be fully trained in 12 weeks, but they offered ongoing support following that period. The decision that a young person has completed their training

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<sup>181</sup> H M Government, **Valuing People Now: a new three-year strategy for people with learning disabilities** (2009), available from [http://base-uk.org/sites/base-uk.org/files/%5Buser-raw%5D/11-06/valuing\\_people\\_now\\_strategy\\_.pdf](http://base-uk.org/sites/base-uk.org/files/%5Buser-raw%5D/11-06/valuing_people_now_strategy_.pdf).

<sup>182</sup> Halcrow Group Limited, **Travel Training: Good-practice guidance** (2005), available from [http://www.tfgm.com/accessible\\_transport/Documents/training\\_guide.pdf](http://www.tfgm.com/accessible_transport/Documents/training_guide.pdf).

<sup>183</sup> **Trafford Independent Travel Training**, available from <https://www.trafford.gov.uk/residents/schools/docs/independent-travel-training.pdf>.

is made by the parents, the trainer and the young person together. Over a period of six years it trained 150 students<sup>184</sup>. More recently, children with learning difficulties in Manchester have been offered travel training by Pure Innovations, a charity based in Greater Manchester<sup>185</sup>. Since July 2010 over 100 young people have taken part in the scheme and over 90% are still travelling independently.

The Autistic Society Greater Manchester Area<sup>186</sup> developed a programme for travel trainers of people with autistic spectrum disorders following an eighteen month project. This involved classroom exercises and journeys with a trainer on a one-to-one basis to provide experience and give the confidence to make unaccompanied journeys and travel buddies.

One example where travel training was part of a package of measures which was shown to encourage more travelling is the work by Logan and colleague in Nottingham<sup>187</sup>. They offered a treatment programme involving the provision of information (e.g. about resuming driving and about alternatives to cars and buses), the use of minor aids or adaptations such as walking sticks, and overcoming fear by providing travel training. There were 86 people who had had a stroke in the previous 36 months in the intervention group and 82 similar people in the control group who received only leaflets describing local transport services for disabled. Those in the intervention group were more likely to get out of the house as much as they wanted and made more trips than the control group (37 compared with 14 after 4 months and 42 compared with 14 after 10 months). This suggests that the intervention was effective at increasing outdoor mobility after a stroke.

The Bus in the Classroom<sup>188</sup> is a scheme in the US in which transport staff (drivers and office staff) teach school students with special educational needs the life skills necessary to be safe in and around the school bus. It was found that all the students taught showed gains in transport safety skills. The students became safer and better behaved on and around the bus.

The visual mapping scheme<sup>189</sup> provided by Angus Council in Scotland is an innovative programme which included travel training linked to the extension of a bus route to assist independent bus travel for clients experiencing learning disabilities attending an adult resource centre in Montrose which did not have a direct bus service. The nearest bus stop was a ten minute walk away so most clients were collected and returned by car or used the resource centre's own transport. A bus route was extended to the resource centre once in the morning and once in the evening to coincide with the centre's normal working hours. As

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<sup>184</sup> **Manchester Travel Training Partnership**, available from <http://www.mttp-travel-training.org/>.

<sup>185</sup> Greener Journeys, Pure Innovations, **Bus 2020: A Manifesto for the next Parliament** (2013), available from <http://www.greenerjourneys.com/wp-content/uploads/2013/09/Bus-2020-A-Manifesto-for-the-next-Parliament.pdf>.

<sup>186</sup> See note 9.

<sup>187</sup> See note 76.

<sup>188</sup> Meslin P, **The Bus in the Classroom: Building Independence Life Skills**, available from <http://www.schoolbusfleet.com/article/710648/the-bus-in-the-classroom-building-independence-life-skills>.

<sup>189</sup> Scottish Government, **Visual mapping scheme: Angus Council**, available from <http://www.scotland.gov.uk/Publications/2006/05/16145515/9>.

more people used the service (both resource centre clients and local residents) more services were put on. In mid-2002 4 people used the service. By April 2005 this had grown to 43. The people using the centre were helped by a visual mapping scheme. This involved taking clients on the journey taking photographs of landmarks and adding captions (e.g. 'This is where I catch my bus'). They carried the photos in a wallet. The clients were accompanied on their journeys until they and their carers were confident that the journey could be made safely. The bus stop in the town centre for the ride to the day centre has been marked with a large yellow triangle to make it a clear landmark.

One important issue is that there can be problems for people who have received travel training when bus routes change because they then have to learn the new routes<sup>190</sup>.

Travel Buddy schemes are usually aimed at people who are able to use public transport but who require extra short term support, boosting their confidence and capability and enabling them to become independent. For example, Transport for London offers advice<sup>191</sup> on planning a journey using an accessible route and can provide a mentor to accompany the traveller for a few journeys to help him or her gain confidence and become an independent traveller. Similarly, The Travel Buddy project<sup>192</sup> run by the Brandon Trust is a service offering alternative travel support for adults and young people with learning disabilities. The Travel Buddy teaches people how to travel safely, confidently and independently by helping with road safety and awareness skills, planning a route, and ways to stay safe whilst out and about. All their travel buddies have completed a structured training programme giving them knowledge about bus travel, and the skills and experience to help other people. In these schemes the emphasis is on practical aspects of gaining experience in making a journey rather than classroom learning. Often the accompanied trips start from the bus stop or railway station. SYSTRA<sup>193</sup> found about concerns about this aspect of accompanied journeys in the work with focus groups in the West Midlands because the participants wanted the accompaniment to start at their home rather than at the transport stop or station.

### *5.2.2 Providing experience in travelling*

Another approach to giving people with mental impairments the confidence to travel is to give them the experience of various aspects of travelling by specific modes.

For example, staff at York railway station found that there was a growing number of elderly, confused people using the station and railway<sup>194</sup>. When this was discussed with the British

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<sup>190</sup> See note 97.

<sup>191</sup> Transport for London, **Learn to use public transport**, available from <https://tfl.gov.uk/transport-accessibility/learn-to-use-public-transport?intcmp=5334>.

<sup>192</sup> Brandon Trust, **Travel Buddy project**, available from <https://www.brandontrust.org/information-and-support/travel-buddy-project/>.

<sup>193</sup> See note 97.

<sup>194</sup> Alzheimer's Society, **The Public Transport Pilot (Best Practise Guidance) Bus, train and Taxi services: A dementia-friendly approach to public transport services**, produced in collaboration with the British Transport Police, Dementia Action Alliance and Dementia Friendly Communities.

Transport Police (BTP) the latter appointed a member of its staff as a champion for the dementia-friendly agenda. She set up a supported travel scheme in which the BTP took groups of people affected by dementia and their carers on train journeys with funding provided by some of the train operating companies. Feedback from the service users was very positive, with most people saying that they would never have travelled by train, but now, having been on a supported journey, they would travel again on their own or with a carer.

West Yorkshire Combined Authority offers bus station tours in which the bus station managers provide group tours for people with a learning disability; in practice this is often a group of people from a SEN school, a group of people who are being trained to travel independently or a group from an advocacy group such as Mencap<sup>195</sup>. The tours introduce people to the bus station, the travel centre and the security staff, explaining about Safe Places Schemes (see Section 5.5.5) and how to access information and help points, and pointing out the CCTV cameras. The overall aim is to reassure people that the bus stations are safe places and there are staff on hand to assist if passengers have any problems

Transport for London (TfL) provides Bus Days<sup>196</sup>. Travel mentors and local disability groups work with local bus companies and the Metropolitan Police's Safer Transport Policing teams to set these up. These events cover all aspects of travelling on public transport and how to remain safe on the transport network. Each event is slightly different as it is tailored to the needs of groups who are taking part and the content is developed beforehand by the travel mentors working with the groups. The common content covers, but is not limited to:

- What to check to make sure you are at the correct bus stop;
- Stopping the bus when you are at the bus stop;
- Talking to the driver and what to do if there is a problem with your fare;
- Where to sit on the bus;
- How to stop the bus;
- How to be safe on your trip;
- Diversion of a bus route.

Another approach is cycle tryout schemes. For example, Positive Spin is a project to enable people with dementia and their carers to cycle funded by the London Borough of Lambeth<sup>197</sup>. Eight sessions were held on Clapham Common in the summer of 2015, using four cycling instructors and a variety of types of bicycle. The outcomes identified included social benefits (allowing those attending to make relationships independently of the instructors), the opportunity to assess risk and facilitate learning for all participants, giving people with dementia a sense of freedom to move around independently and under their own control,

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<sup>195</sup> Ward E, Accessible bus stations and stops make travel easier in West Yorkshire, **Eurotransport**, **13** (2015), 34-36.

<sup>196</sup> Transport for All, **Travel Training Information**, available from <http://www.transportforall.org.uk/public/training/>.

<sup>197</sup> Cycle Training UK, **Positive Spin 2015 Report**, available from <http://www.cycletraining.co.uk/news-and-info/articles-and-reports/reports/positive-spin-2015-report.pdf>.

opportunities to reminisce about cycling and other things, and exercise. The Active in Dundee project included cycle tryout sessions for adults with mental health problems<sup>198</sup>.

### 5.2.3 The effects of interventions to enhance travel skills

The interventions discussed in this section would all help in various ways to help travellers with mental impairments in making journeys, particularly to increase confidence in making a journey, as shown in Table 29. Travel training would help a person with a mental impairment to learn where decisions would have to be made, what the possible outcomes are, how to decide, where it would be necessary to communicate with another person, and the type of information that would need to be given. Strategies for remembering and obtaining information can be learnt if necessary. The various schemes offering travel experience would offer similar information about using a particular mode. Both techniques help to reduce the uncertainty associated with travel.

Table 29 The mental skills used in travel that may be enhanced by interventions to improve them directly

	Ability to remember	Comprehension	Decision making	Interpersonal communication	Confidence in travelling alone	Ability to behave appropriately
Travel training	•	•	•	•	•	•
Experience of travelling		•	•	•	•	

## 5.3 Interventions to simplify the journey

### 5.3.1 Making the environment more legible

One way to simplify walking journeys is to make the local environment easier to interpret. Blackman and colleagues<sup>199</sup> reviewed the literature on accessibility for people with dementia. They examined indoor environments and concluded that environmental cues are important for people with dementia, and that for some people, a sequence of cues may be helpful. They argue that locational and directional information needs to be presented in a way that takes account of their impairment, but that people with dementia may be confused and disoriented by an over-abundance of information. Wayfinding information needs to be located systematically at decision points, well lit, at eye level and taking into account the stooped posture of older people. They suggest that signs should be simple with large dark text on a light background in clear colours. Whilst these design criteria were based on analysis of indoor environments because of the lack of research into outdoor environments, it seems likely that they are equally valid out of doors. They suggest that long, uniform, repetitious streets and

<sup>198</sup> Physical Activity and Health Alliance, **Dundee Travel Active**, available from <http://www.paha.org.uk/CaseStudy/dundee-travel-active>.

<sup>199</sup> Blackman T, Mitchell L, Burton E, Jenks M, Parsons M, Raman S and Williams K, The accessibility of public spaces for people with dementia: A new priority for the 'open city', **Disability & Society**, **18** (2003) 357-371, available from <http://www.tandfonline.com/doi/pdf/10.1080/0968759032000052914>.

buildings frontages could be difficult, and so short, direct routes without dead ends and small well-defined spaces are likely to be less disabling. They suggest that plain, smooth, level, non-slip and non-reflective paving is likely to be the most effective surface, and that poor lighting, inadequate maintenance, uneven surfaces in high friction materials such as cobbles or gravel and paved areas with complicated mixed patterns are all likely to lead to disorientation. In another paper, the same research team identified six design principles relevant to the outdoor environment<sup>200</sup>:

- Ensure environment is familiar;
- Ensure environment is legible;
- Ensure environment is distinctive;
- Ensure environment is accessible;
- Ensure environment is comfortable;
- Ensure environment is safe.

These design principles can be used to assist people with dementia and other cognitive impairments to negotiate and use their local environments.

In their study using in-depth interviews, focus groups and participant observation in the Gospel Oak neighbourhood in North London to examine the relationship between the fear of crime and mental health, Whitley and Prince<sup>201</sup> found that changes in urban design through regeneration schemes and community safety measures such as concierges and security gates gave people with mental health issues more confidence to travel in their local environment.

### *5.3.2 Parking provision*

One way to simplify car journeys is to provide parking close to the destination. For people with agoraphobia this enables them to travel without the need to walk long distances which some of them find difficult. It also enables parents of children with behavioural impairments to escort them away from public places quickly if necessary.

In the United Kingdom 'Blue Badges' are issued to enable parking without charge or time limit in places such as on-street disabled bays and at on-street parking meters and play and display machines. They also enable badge holders to park on yellow lines for up to three hours unless a ban on loading or unloading is in force.

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<sup>200</sup> Mitchell L, Burton E, Raman S, Blackman T, Jenks M, Williams K, Making the outside world dementia-friendly: Design issues and considerations, **Environment and Planning B: Planning and Design**, 30 (2003) 605–632, available from <http://www.envplan.com/abstract.cgi?id=b29100>.

<sup>201</sup> See note 82.

There are two types of eligibility criteria to obtain a Blue Badge: Type 1 is 'Eligible without further assessment'<sup>202</sup> <sup>203</sup>. The criteria for this include receiving the Higher Rate of the Mobility Component of the Disability Living Allowance or receiving 8 points or more under the 'moving around' activity of the mobility component of Personal Independence Payment (PIP). Other grounds include being registered blind or receiving certain benefits associated with being in the armed forces. The second type of eligibility is Type 2 which is 'Eligible subject to further assessment'. Eligibility under this criterion involves demonstrating that the person concerned is unable to walk or is unable to walk very far without experiencing considerable difficulty, for example because of excessive pain or breathlessness. The criteria explicitly exclude medical conditions such as autism and psychological/behavioural problems as qualifications for a badge.

The Personal Independence Payment (PIP) scheme has replaced the Disability Living Allowance (DLA) scheme for people of working age. Some people who received a Blue Badge under the DLA scheme have found themselves no longer eligible under the PIP scheme. For example, a number of members of Anxiety UK which represents people with agoraphobia have lost their blue badges as a result of the change. As Anxiety UK's CEO, Nicky Lidbetter, said: *"As a sufferer of agoraphobia, public transport was a no-go area for me. Like most people with agoraphobia, public transport is terrifying as it is difficult to escape if panic sets in. When I began to recover and be able to travel further from my home on my own, the bus or tram was never an option for me to do essential journeys like the food shopping or attending medical appointments, let alone do the school run or work to build up two mental health charities. Having a blue badge allowed me to get some of my independence back as I felt safe going to GP or supermarket, knowing that if I felt like I needed to get out quickly as a result of a panic attack, I could do so."* For a time she was housebound but after a lot of work on her part and the support of her family and therapist, she is now able to do much more and has become a well-respected leader in mental health, both in Manchester and the UK. She credits having a blue badge with helping her get her independence back<sup>204</sup>.

This issue of eligibility for a Blue Badge for people with mental impairments was raised by a number of bodies when a consultation exercise about PIP was conducted. For example, Mencap<sup>205</sup> has argued that eligibility for a Blue Badge should be retained for people with a learning disability who need one. They argue that there is too much emphasis on physical disability and that there should be acknowledgement that a person's mobility may be

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<sup>202</sup> Department for Transport, **Can I Get a Blue Badge? A guide from the Department for Transport for people living in England** (2013), available from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/197719/can-i-get-a-blue-badge.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/197719/can-i-get-a-blue-badge.pdf).

<sup>203</sup> Department for Transport, **The Blue Badge Scheme Local Authority Guidance (England)** (2014), available from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/519091/blue-badge-scheme-local-authority-guidance-paper.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/519091/blue-badge-scheme-local-authority-guidance-paper.pdf).

<sup>204</sup> Anxiety UK, **Is mental health taken as seriously as physical health when applying for a blue badge?** Note.

<sup>205</sup> Mencap, **Response to the Consultation on Personal Independence Payment (PIP) and eligibility for a Blue Badge** (2012).

significantly impaired as a result of an intellectual or cognitive impairment. They say that some people who are able to walk need to park near to shops or services due to challenging behaviour or the nature of their disability which could put them or others at risk. There are people who may experience extreme anxiety and stress when travelling somewhere new or who may find it difficult to cope in busy environments. The anxiety may manifest as challenging behaviour which means that, for their own safety and that of others, it is important that they can reach a 'safe space' quickly, which means that easy access to their vehicle is imperative. Similarly, the Alzheimer's Society<sup>206</sup> made the case for Blue Badges for people with dementia. It does not support the idea that all people with dementia should be automatically eligible for a blue badge because that would increase dependency and reduce independence. They suggest that a letter from a GP which states that the symptoms of dementia have progressed to a stage where their mobility is impaired because of either physical problems or concerns about the safety of the person with dementia, should be sufficient. They argue that disorientation caused by, for example, a large car park, may lead to the person with dementia becoming aggressive or anxious. This means that it may be impossible to leave the person with dementia in the car alone or for him or her to be dropped off on the street while the car is being parked elsewhere. They may become very clingy to a carer, making leaving them on the street whilst the car is being parked risky.

The Welsh Government recently changed the eligibility criteria for Blue Badges in Wales. In Wales the Type 2 criteria (Eligible subject to further assessment) includes 'Applicant, as a result of a cognitive impairment is unable to follow the route of a familiar journey without the assistance of another person'<sup>207</sup>. The Guidance<sup>208</sup> says that applicants who fall into this category who are unable to clearly demonstrate their needs, may be passed for 'further assessment' to an Independent Advisory Service who will be responsible for making a decision in these cases. This criterion applies to people who have difficulty planning or following a journey, to such an extent that they need constant supervision. Applicants may also apply under this criteria if they are outside the qualifying age for PIP or they choose not to apply for the benefit. According to the Guidance, this may capture people with:

- Autism;
- Alzheimer's or dementia;
- Stroke survivors;
- Learning disabilities;
- Mental health;
- Head injuries.

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<sup>206</sup> Alzheimer's Society, **Alzheimer's Response to Transport Wales Blue Badge Wales Consultation** (2011), available from [http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1059](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1059).

<sup>207</sup> Welsh Government, **Blue Badge Scheme in Wales: Guidance to Local authorities** (2015), available from <http://gov.wales/docs/det/publications/150109-blue-badge-la-en.pdf>.

<sup>208</sup> Welsh Government, **Blue Badge Local Authority Verification Toolkit** (2014), available from <http://gov.wales/docs/det/publications/150123bluebadgetrainingen.pdf>.

This is not an exhaustive list. This criterion is not entirely based on a diagnosis of conditions, but requires that they need to have constant supervision when they are out. The information to demonstrate eligibility would be a letter of support from a relevant healthcare professional such as Child and Adolescent Mental Health Services (CAMHS), Paediatricians, Psychiatrists, Psychologists, attendance at a Memory Clinic or being registered on a local authority Learning Disability Register.

It should be noted that the criteria used in Wales would meet some of the issues raised by campaigning groups such as Mencap<sup>209</sup> and the Alzheimer's Society<sup>210</sup>, but not those raised by Anxiety UK<sup>211</sup>. More specifically, it seems unlikely that the criteria would apply to a person who drives alone since it seems very unlikely that they would meet the criterion of being constantly supervised when away from home, but it might apply to a person with a mental impairment who is taken by car by a carer and cannot be left unsupervised.

### 5.3.3 Special transport services

Special transport services such as dial-a-ride provide door-to-door journeys reducing the number of decisions that have to be made and the amount of information required to make a journey. However they are not always available to people with mental impairments or they may have to be accompanied by a carer.

Transport for London<sup>212</sup> provides 'assisted transport' for older and disabled people, for whom public transport is not accessible. Three services are available: Dial-a-Ride, Taxicard and Capital Call. Taxicard provides its members with a number of subsidised taxi trips per year. Capital Call provides a similar service in areas where there are not many taxis by giving an annual budget to be used to subsidise taxi fares.

In the West Midlands, CENTRO<sup>213</sup> (now Transport for the West Midlands) provides 'Complementary Travel Services' for people with mobility difficulties living in areas with low demand, particularly low density and rural areas, through demand responsive Ring and Ride (the local name for dial-a-ride), Taxibus and community transport in order to match underused transport capacity to unmet demand for transport, particularly by those unable to use conventional public transport services. Travel training and travel buddies are also part of the scheme. In the focus group discussions with people with learning disabilities carried out for CENTRO by SYSTRA<sup>214</sup> Ring and Ride was mentioned as being invaluable by some of the participants because it meant that they could go out in the evening, because they were

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<sup>209</sup> See note 205.

<sup>210</sup> See note 206.

<sup>211</sup> See note 204.

<sup>212</sup> Transport for London, **Getting Around London** (2015), available from

<https://tfl.gov.uk/cdn/static/cms/documents/uploads/forms/getting-around-london-large-print.pdf>.

<sup>213</sup> CENTRO, **Towards a World Class Integrated Transport Network: Supporting Growth and Regeneration in the West Midlands** (2013), available from <https://www.centro.org.uk/media/541574/WCCE-E9-Towards-a-World-Class-Integrated-Transport-Network.pdf>.

<sup>214</sup> See note 97.

nervous about using the bus then. However demand for the Ring and Ride service in the West Midlands has declined with investment in buses, trains and trams, and stops and stations to make them more accessible<sup>215</sup>.

### 5.3.4 The effects of interventions to simplify the journey

These interventions work in different ways to simplify the journey, but they would all increase the confidence of some people with mental impairments. Improvements to the environment would help to simplify the journey by assisting in decision making by providing information in appropriate ways and making the local environment easier to interpret.

Parking provision can assist people with mental impairments such as agoraphobia to travel by car and avoid walking long distances. They can also assist parents with children with behavioural problems who need to be taken by car and may need to be removed from the proximity of strangers and unfamiliar surroundings at short notice.

Special transport services such as dial-a-ride take people door to door and so reduce the need for decisions, which helps people for whom that is difficult or those with poor memory. They can also help people with behavioural difficulties since they would not have to make their own way in unfamiliar surroundings or be left alone during the journey.

Table 30 indicates how these interventions may help with addressing the lack of mental skills used in making a journey.

Table 30 The mental skills used in travel that may be enhanced by simplifying the journey

	Ability to remember	Comprehension	Decision making	Interpersonal communication	Confidence in travelling alone	Ability to behave appropriately
Making the environment more legible		•	•		•	
Parking provision					•	•
Special transport services	•	•			•	•

## 5.4 Interventions to provide clear travel information

### 5.4.1 Inclusive travel guides

Inclusive travel guides provide information about barriers to travel for people with impairments, with some of them aimed specifically at people with mental impairments. They explain about possible barriers and how to overcome them to give greater confidence prior

<sup>215</sup> CENTRO, **Prospectus for Accessible Transport**, draft document, available from <http://www.wmita.org.uk/media/2949/item-12-appendix-prospectus-for-accessible-transport.pdf>.

to making journeys. There are some that have been designed explicitly for people with cognitive impairments and mental health conditions such as the 'Your Journey' guide issued by NEXUS<sup>216</sup>. The latter was designed by local children with autism and Asperger's syndrome. It was produced with input from the National Autistic Society, but mainly by listening to the points made by the students and also taking them out on public transport to see what their specific issues were<sup>217</sup>. Each individual using the guide uses the basic information from the text in the travel booklet to help them to design their own personal journey plan by using Manga expressions and identifying their feelings to tackle any insecurities they have; this then means they can build up their own confidence with their parents and teachers in their own unique way.

NEXUS<sup>218</sup> has also produced a guide about community safety for people with learning disabilities based on information gained by talking to people with this condition. It gives advice on:

- Personal safety and security;
- Things to take on the journey;
- Road skills such as using a pedestrian crossing and the Green Cross Code;
- Using the bus and using the Metro;
- Asking for assistance;
- Contact information.

#### *5.4.2 Pre-journey information*

Clear pre-journey information is required on websites and in leaflets based on awareness of the needs and abilities of people with mental impairments. The United Nations Convention on the Rights of Persons with Disabilities<sup>219</sup> states the rights of disabled people which include the need to provide information in an appropriate form and to provide assistance to access information. As discussed in Section 1, the Equality Act 2010 requires information being provided as part of a reasonable adjustment to be provided in an accessible format.

Clear print standards help to maximise the legibility of print publications and should therefore be used for all printed materials<sup>220</sup>. The Clear Print Standard requires a minimum font size of 12 point. A simple font that spaces letters out should be used. Italics, underlining, simulated handwriting, unusual shaped letters and decorative typefaces should be avoided. Text should be horizontal, not on a slant. It should be aligned text left for maximum legibility. Line lengths

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<sup>216</sup> NEXUS, **Your journey: Everything you need to know when you're out and about** (2014), available from <http://www.nexusteachingzone.org/index.htm/files/Your%20Journey%20A6.pdf>.

<sup>217</sup> Ditchburn R (NEXUS), Individual communication to author 25 February 2015.

<sup>218</sup> NEXUS, **Travel Safe: A guide about community safety** (2010), available from <http://informationnow.org.uk/files/download/52>.

<sup>219</sup> United Nations, **Convention on the Rights of Persons with Disabilities**, Article 20, Personal mobility, available from <http://www.un.org/disabilities/convention/conventionfull.shtml#top>

<sup>220</sup> Office for Disability Issues, **Accessible Communication Formats**, available from <https://www.gov.uk/government/publications/inclusive-communication/accessible-communication-formats#easy-read-and-makaton>.

should be between 60 and 70 characters, roughly 12 to 18 words, per line and hyphens to split words between lines should be avoided. Sections and chapters should be clearly defined with headings. Headings and page numbers should be kept in the same place on each page. Paragraphs should be short and line spacing should be used between paragraphs. Wide margins should be used. Boxes can help emphasise or highlight important text. A contents page should be included.

The Easy Read format was created to help people with learning disabilities understand information easily<sup>221</sup>. It uses pictures to support the meaning of text. It can be used by a carer to talk through a communication with someone with learning difficulties. Guidelines on producing Easy Read materials include:

- Keep the number of pages to 24 or less. If there are more, break the text up into more than one publication;
- Keep sentences short – they should be no more than ten to 15 words;
- Each sentence should have just one idea and one verb;
- Use 14 point font size;
- Make sentences are active not passive: “we are following up your complaint” (active tense) not “your complaint is being followed up” (passive tense);
- Take out words that are not needed, for example, say ‘for 14 days’ not ‘for a period of 14 days’;
- Include a glossary explaining abbreviations and jargon, and an index, at the end of the document;
- Use full words not acronyms;
- If you need to use difficult words or ideas, say what they mean – do this in the next sentence, not as part of the same sentence;
- Use a different colour or bold type but keep a good contrast with the paper;
- Use pictures to support the meaning of your text.

In the MAPLE Project<sup>222</sup> it was found that that many people find maps, particularly complex ones, difficult to read. However, the transport systems in large urban areas are complex, so effort has to be put into making the information simple and tailored to the needs of individuals as far as possible. The project report shows an example of a ‘spider map’ of London’s bus and Underground map which was designed in conjunction with CHANGE a voluntary organisation that supports people with cognitive impairments. The maps show the public transport routes from a particular point in London, including an enlarged area around the trip origin showing where bus stops are and the public transport routes going away from

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<sup>221</sup> Leat M, **A Guide to Producing EasyRead Information**, The Clear Communication People Ltd (2009), available from [http://www.easyonthei.nhs.uk/literature\\_113517/The\\_Clear\\_Communication\\_People-Guide\\_to\\_producing\\_easy\\_read\\_information](http://www.easyonthei.nhs.uk/literature_113517/The_Clear_Communication_People-Guide_to_producing_easy_read_information).

<sup>222</sup> MAPLE, **Improving Mobility and Access for People with Learning Disabilities and Cognitive Impairments**, Brochure (2003), available from <http://www.ttr-ltd.com/downloads/pdf/MAPLE-pages.pdf>.

it in approximate geographical locations, with key stops shown. Similar maps are used on bus shelters in London nowadays to show the bus routes and locations served by the bus stop.

Web-based information is not useful for many people with dementia as they do not have internet access<sup>223</sup>. This prevents them from finding out about all the support that is available. They require information to be displayed in stations and to be available by post if requested by telephone. Relevant travel information can be displayed in GP's surgeries and at pharmacies and other places that people with dementia visit.

#### *5.4.3 Clear signs*

Simple, clear signs during the journey provide clear guidance about the route to take to reach the next decision point and give reassurance.

In the United States, Hunter-Zaworski and Hron<sup>224</sup> carried out interviews with four trainers of people with a range of physical and mental impairments, one public transport user with a brain injury and four people who co-ordinated programmes for disabled people and asked members of the Special Transportation Fund Advisory Committee of Lane Transit District in Eugene in Oregon in the USA to rate communications methods that a public transport operator could provide to best assist people with cognitive impairments to make a successful journey. They found that colour and visual symbols are helpful to people with cognitive impairments. Their review of the literature confirmed that signs should have symbols and pictograms, large printing, consistent placement and proper lighting. However, they also argue that pictograms should be complemented by written messages, or by other sensory information such as vibration, auditory or tactile to reinforce the message. The idea of including text explanation of pictograms is also acknowledged in the report on the MAPLE project<sup>225</sup>, where it is argued that a system of pictograms or icons is a language that has to be learnt and so text translation of the images should be included. They also argue that there should be absolute consistency in the form of icons and any colouring that is used. More generally they argue that signs should be both intuitive and uncomplicated, avoiding redundant information. They show the example of a sign used in Merseyside which consists of a footprint with the word 'BUS' plus a red arrow in it which is painted on the pavement, which conveys instantly that it is showing the pedestrian route to the bus station or nearest bus stop. This information is also shown in the report by the International Transport Forum<sup>226</sup>.

The Office for Disability Issues<sup>227</sup> provides the following advice about posters, boards and leaflets:

- Keep the design simple;

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<sup>223</sup> See note 73.

<sup>224</sup> See note 8.

<sup>225</sup> See note 222.

<sup>226</sup> International Transport Forum, **Cognitive Impairment, Mental Health and Transport: Design with Everyone in Mind** (2009), available from <http://www.itf-oecd.org/sites/default/files/docs/09cognitive.pdf>.

<sup>227</sup> See note 220.

- Avoid background graphics that make text difficult to read;
- Keep essential information, for example event details, grouped together;
- Use lower case rather than capitals.

#### *5.4.4 Audio Visual Information (AVI)*

Providing both recorded announcements and visual displays on screens on buses and trains showing information such as the name of the next stop and reminders about the route number can be very useful to people with mental impairments. Providing both simultaneously helps many people who require time to assimilate information, but there may be a danger of information overload for some people.

#### *5.4.5 Mobile phone apps*

Two new forms of technology which have emerged in recent years are mobile phones, many of which can be used to interact with the internet, and GPS technology, which can provide locational information about people, landmarks and vehicles. Combining these two technologies means that users can obtain detailed navigational information and communicate with others such as carers and transport staff whilst travelling using a device that fits into a pocket. Much of the software comes in the forms of ‘apps’ (short for ‘applications’) that are provided by commercial companies, often linked with publically-provided information such as maps and timetables. Locational information from satellites is provided for free from satellites funded by the US Department of Defense.

Mobile phone apps can provide real time information during walk and bus journeys which some people with mental impairments may find useful. For walk journeys this may be information about the direction to take at junctions. For bus journeys it may be information about bus arrivals and when to get off the bus. They can also alert carers if the user leaves their planned route. Sohlberg and colleagues<sup>228</sup> suggested various features that could be incorporated into navigation devices, based on their discussions with people with cognitive impairments, carers and public transport staff:

- Beeper to locate companions;
- Help button;
- Repeating of directions;
- Link to carer;
- Audio/visual option;
- Ability to personalize directions;
- Provision of training for device use;
- Provision of device updates;
- Alert to tell rider when to get off the bus;
- A link with bus system GPS when used on a bus;
- Ability to track riders who are in the system;

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<sup>228</sup> See note 107.

- Ability to make route corrections mid-route;
- Ability to provide the bus driver with medical and emergency information.

Nexus<sup>229</sup> identified some features of apps that provide benefits for people with intellectual impairments:

- Direct speech output for journey planning and wayfinding;
- Appropriate queuing arrangements at stations and bus stops;
- Easy to read location signs;
- Audio system for locating ticket machines;
- Timetable and real time public transport information with audio output;
- Audio information about service disruptions and temporary bus stop location;
- On buses, a personal facility to request the bus to stop and audio announcement if not actually at bus stop;
- At stations and bus stops, audio information on connecting services, and how to reach the final destination.

Fickas and colleagues<sup>230</sup> in the USA looked at four different ways of providing navigation information for pedestrian wayfinding to people with cognitive impairments: 1) aerial map image, 2) point of view map image, 3) audio direction with no image and 4) text-based instructions with no image. 20 people with cognitive impairments due to acquired brain injury walked four equivalent routes using the four different ways of providing information delivered via a wrist-worn navigation device. The participants were recruited from two local assisted living facilities by asking staff to refer potentially interested residents with cognitive impairments which affected of attention, memory or executive functions who experienced difficulty with navigation. A total of 22 participants were referred. Of these, 20 were able to complete the navigation routes. 12 of the 20 participants found the audio method most helpful, because they perceived the information to be easier to follow, and it did not require them to look at the screen. None of the participants found the text-based instructions most helpful. Nine out of the 20 found the aerial photos least helpful because they found it hard to understand where the arrow was pointing and to relate the pictures to where they were walking. The audio method was less conspicuous than the other methods and so presented a lower risk of drawing attention to vulnerable users.

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<sup>229</sup> Nexus, **Review of Assistive Technology for Blind and Partially Sighted Passengers**, Final Report (2014).

<sup>230</sup> Fickas S, Sohlberg M K and Hung P F, Route-following assistance for travelers with cognitive impairments: A comparison of four prompt modes, **International Journal of Human-Computer Studies**, **66** (2008),876–888, available from [http://ac.els-cdn.com/S1071581908000797/1-s2.0-S1071581908000797-main.pdf?\\_tid=df05f4aa-19d5-11e5-a73d-00000aab0f27&acdnat=1435084386\\_26d3f40ba746c4f6938063788ffb58b9](http://ac.els-cdn.com/S1071581908000797/1-s2.0-S1071581908000797-main.pdf?_tid=df05f4aa-19d5-11e5-a73d-00000aab0f27&acdnat=1435084386_26d3f40ba746c4f6938063788ffb58b9).

Chang and colleagues<sup>231</sup> in Taiwan have developed a prototype wayfinding system for people with cognitive impairments which has three elements: a handheld PDA (portable data assistant), a tracking system and a training system. The system was devised for use indoors, but it could be used outdoors. The PDA's built-in camera scans QR-code tags which have been placed at points where decisions have to be made. (A QR-code tag looks like a two-dimensional barcode; QR stands for quick response). An arrow appears on the screen showing the direction to be followed against an image of the location. The location of the user can be transmitted back over wi-fi to an authorised person who can track where the user is. They carried out experiments with six people with cognitive impairments walking five routes. The participants were recommended by the rehabilitation institutes involved in the study. One participant had difficulty understanding that the photograph told him to push a button on one route, and another bypassed a tag without scanning it and so became lost. Then the participants were asked to find their way along one of the routes without using the navigation aid. Two out of the six participants were successful, suggesting that the system had provided limited assistance with wayfinding.

Livingstone-Lee and colleagues<sup>232</sup> carried out a literature review and concluded that information for wayfinding navigation on the street should provide auditory feedback giving left/right instructions based on the way that the navigator is currently standing, prime individuals about upcoming decision points, limit redundant information, give navigation instructions from the perspective of the navigator and pay special attention to instructions provided at initial orientation, choice points, and destination. They then reviewed mobile phone apps to see whether they were useful for people with brain injuries and other cognitive impairments. A total of 159 apps were identified, 99 for use on public transport and 60 for navigating on the street. Of the 99 for use on public transport, seven were designed for people with cognitive impairments. They identified eighteen useful features that appeared on the seven public transport apps. All of them included trip planning and could be programmed by a carer and all except one included walking instructions and voice instructions. They identified three apps as being particularly noteworthy:

- 'Onthebus', for phones using the Android operating system, which had 14 of the useful features;
- 'Tiramisu' which has been funded by 'crowd-sourcing' by people without cognitive impairments;
- 'TAD' (Travel Assistance Device) which was tested by Barbeau and colleagues<sup>233</sup> as discussed below.

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<sup>231</sup> Chang Y-J, Tsai S-K and Wang T-Y, A context aware handheld wayfinding system for individuals with cognitive impairments, **Proceedings of the 10th international ACM SIGACCESS conference on Computers and Accessibility** (2008), 27-34, available from <http://dl.acm.org/citation.cfm?id=1414479>.

<sup>232</sup> Livingstone-Lee S A, Skelton R W and Livingston N, Transit apps for people with brain injury and other cognitive disabilities: The state of the art, **Assistive Technology**, **26** (2014), 209-218, available from <http://www.tandfonline.com/doi/pdf/10.1080/10400435.2014.930076>.

<sup>233</sup> Barbeau S J, Winters P L, Georggi N L, Labrador M A, and Perez R, Travel assistance device: Utilising global positioning system-enabled mobile phones to aid transit riders with special needs, **IET Intelligent Transport**

The other four apps for use on public transport by people with cognitive impairments, all of which had some useful features, were:

- Wayfinder examined by Davies and colleagues<sup>234</sup> as discussed below;
- ITWP (ITravelWithMyPhone);
- WalkWithMe;
- TravAlarm Denmark.

Of the 60 apps designed for navigating on the street, 14 were aimed at people with cognitive impairments. On these, the most frequently occurring features were a phone locator, voice instructions, being programmable by a carer, and the ability to send notifications to a carer.

The ways in which an app can be used for a bus journey is illustrated by Manduchi<sup>235</sup> who describes a prototype system which provides real-time customized information to people with cognitive impairments (also blind people) through the user's smartphone from wi-fi access points (APs) which have been placed at bus stops and in buses. The idea is that the user would walk to the bus stop and start the app on his or her phone. If the phone is within the transmission range of the AP, the app would prompt the user to connect to the AP in order to receive information. If there is more than one AP within range the user is asked to select the one to connect to. Upon connection the user is informed which bus routes serve the stop and the user selects a desired one. The user is then prompted to select a final destination from a list. The user is then instructed to wait for the bus to arrive. While waiting the app can be interrogated to find the estimated time until arrival. Once the bus has arrived and the phone is within range of the AP inside the bus, the app switches connection to this AP. The user boards the bus and finds a seat. The user receives information about the current location of the bus and tells the user about each stop as it is approached. As the destination is approached, a special announcement is produced giving ample time to prepare for alighting. Just before the bus reaches the user's destination, he or she is prompted to be ready to alight. Once the user has alighted and the bus has departed, the system disconnects from the AP on the bus and goes into sleep mode.

The app was tested in California in the USA with four blind people using three bus stops and one instrumented bus (but nobody with a cognitive impairment). The participants were recruited from the network of acquaintances maintained by the principal investigator on the project. It received positive feedback from the participants who made some suggestions for improvement such as giving more notice of the bus arrival, coping with several buses arriving

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**Systems**, 4 (2010), 12-23, available from <http://digital-library.theiet.org/content/journals/10.1049/iet-its.2009.0028>.

<sup>234</sup> Davies D K, Stock S E, Holloway S, and Wehmeyer M L, Evaluating a GPS-based transportation device to support independent bus travel by people with intellectual disability, **Intellectual and Developmental Disabilities**, 48 (2010), 454–463, available from <http://www.aiddjournals.org/doi/pdf/10.1352/1934-9556-48.6.454>.

<sup>235</sup> Manduchi R, **Transit Information Access for Persons with Visual or Cognitive Impairments**, Final Report for Transit IDEA Project 71, Transportation Research Board (2015), available from <http://www.trb.org/main/blurbs/173013.aspx>.

at the bus stop at the same time and being able to use the device with one hand. The latter two might not apply to people with cognitive impairments, or possibly the first (but there might be other issues).

Davies and colleagues<sup>236</sup> used a mobile Windows-based hand-held computer running Wayfinder software which is commercially available in the UK. Wayfinder Navigator is a mobile GPS application that provides turn-by-turn directions through mobile phone software originally developed by Vodaphone but now available as open-source software. By downloading pre-loaded maps, it can provide directions and different points of interest without Internet connection. Notable features include recorded voice instructions, walking routes, an initial prompt to start the trip, programming of landmarks, notification of 'not your stop' when travelling on a bus, notification to 'get off the bus now', and customized reminders. They carried out a study in the United States involving 23 participants with intellectual impairments who used the device while a control group who used a map and verbal directions for travelling on a bus route. The 23 study participants with intellectual impairments were young people and adults who received support services through either a public school transition program or a community-based developmental disability agency. 73% of participants using the device identified the correct destination bus stop, rang the bell at the proper time and exited at the correct location compared with only 8% of the control group. In a follow-up study<sup>237</sup> 26 people with intellectual impairments took part. They first learned how to use the system by travelling on a training route with a travel trainer. Then they used the system to travel a bus route without accompaniment and without knowledge of the destination. 24 out of 26 of the participants alighted at the correct stop.

Barbeau and colleagues<sup>238</sup> tested a TAD (travel assistance device) which gives real-time audio, visual and tactile alerts to exit the bus using GPS on a mobile phone. Also, it alerts the user and his or her carer if the user deviates from the planned route. A webpage allows a carer to create new itineraries and monitor real-time rider location. The researchers carried out 38 trips to evaluate the reliability of the system and asked students with special education needs (SEN) to carry out 12 trips to identify human interface issues. Of the 38 trips carried out by the researchers, 34 were prompted correctly after the stop prior to the destination and allowing sufficient time to react appropriately. Of the 12 trips by students with SEN, one had an early prompt, 4 a late prompt and 2 no prompt, so only 5 were prompted correctly. They concluded that the system was successful as a concept but that the correct location information for bus stops is critical.

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<sup>236</sup> See note 234.

<sup>237</sup> Stock S E, Davies, D K, Wehmeyer M L, and Lachapelle Y, Emerging new practices in technology to support independent community access for people with intellectual and cognitive disabilities, **NeuroRehabilitation**, 28 (2011), 261–269, available from <http://content.iospress.com/download/neurorehabilitation/nre00654?id=neurorehabilitation%2Fnre00654>.

<sup>238</sup> See note 233.

Riehle and colleagues<sup>239</sup> identified a small set of potentially useful features during development of a public transport app for people with cognitive impairments. The idea is to use a GPS enabled smart phone to provide location-based memory cues to people with cognitive impairments so that they can use public transport more effectively. The idea is that a carer schedules trips ahead of time and stores them in the mobile phone directly or via an internet-based application. When the scheduled time arrives the software application wakes up and starts the tracking functions. These continue until either an OFF-ROUTE signal is received or the BUS\_EXIT alert is triggered. The user can access an alarm interface by shaking the phone vigorously and then touching the large red button on the screen to contact their carer. The system uses data on public transport schedules and routes in the Minneapolis area published by the Minneapolis Metropolitan Council using General Transit Feed Specification (GTFS) which is available to the public for over 250 cities worldwide mostly in the USA but none, apparently, currently in Britain. When the distance between the exit stop (indicated by its longitude and latitude) and the current GPS reading reaches some predefined distance, an alarm is triggered. An algorithm to detect user errors such as boarding the wrong bus is included: this detects departures from the planned route. Various aspects of use of the software were tested by the developers and, in a test on 41 trips, the exit alarm was generated on 100% of trips.

Liu and colleagues<sup>240</sup> developed a mobile phone app that uses wi-fi rather than GPS for navigation so that it can be used in metro systems where GPS signals cannot be accessed. They carried out tests on the Taipei Metro with six people with cognitive impairments. These participants were identified with assistance from with five Taipei-based rehabilitation hospitals. Reminders were given by sound or vibration of when to get off the bus, when the next stop was coming, when users were going the wrong way, and when they had missed a stop. Carers were automatically informed of the person's location. The users were positive about using the device with two of them who were initially reluctant to use the device being willing to do so after the trial. The users preferred the vibration prompt to the sound prompt.

Compagnon<sup>241</sup> is a system that can be used to provide guidance on all forms of public transport. It has been developed by Mass Factory Urban Accessible Mobility, S.L. (Mass Factory), a high-tech, spin-off company of the Universitat Autònoma de Barcelona (UAB), established in October, 2012. The system, which is available on Android and in the near future in IOS, consists of three modules: a mobile app for the user, a web app to plan the trips and a control panel for a control centre and carers to monitor the user. The control centre has

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<sup>239</sup> Riehle T H, Anderson S M, Lichter P A, Brown A W and Hedin D S, Public transportation assistant for the cognitively impaired, **Engineering in Medicine and Biology Society, EMBC, 2011 Annual International Conference of the IEEE** (2011), 7585–7588 (IEEE, Boston, MA), available from <http://ieeexplore.ieee.org/xpl/articleDetails.jsp?arnumber=6091870>.

<sup>240</sup> Liu H-H, Chen Y-J, Chang Y-J and Chen W-H, Mobile guiding and tracking services in public transit system for people with mental illness, **TENCON 2009–2009 IEEE Region 10 Conference** (2009), 1–4 (IEEE, Singapore), available from <http://ieeexplore.ieee.org/xpl/articleDetails.jsp?arnumber=5396107>.

<sup>241</sup> App&Town, **Compagnon**, available from <http://www.appandtown.com/compagnon.html>.

overall management of the system, carries out the route planning, supervises and assist the users, and monitors any faults in the system (battery levels, date and time of the trip, GPS accuracy and so on). The web app is programmed with routes involving all forms of transport. On the street it tells the user to turn left and right at junctions, and, when necessary, gives more detailed information; photos can be downloaded to give more precision on the route. At the bus stop it tells the user when the correct bus is arriving and then when to alight from the bus. There is a demonstration of the use of the system on the website. It has been used in Barcelona by people with cognitive impairments to enable them to travel on public transport to attend painting workshops and in some cases to go to the neighbourhood library. It was found that, after two weeks of training with the system, they had improved their self-esteem to the extent that there was no need for a social worker to escort them to these places.

The report by Institution of Engineering and Technology and ITS-UK<sup>242</sup> discusses three apps which could be useful for people with mental impairments, possibly after some adaption:

- Navigon which uses GPS linked with digital mapping to provide guidance on the street with spoken guidance, pedestrian directions, a 'take me home' feature and links to the user's contact list to provide directions to a selected contact;
- Blind Square uses GPS to determine the user's location and then links with other systems to provide spoken information about the nearest street intersections and local facilities;
- SeeingAssistant-Move provides route planning, location search and 'where-am-I' features amongst others.

#### *5.4.6 The effects of interventions to provide clear travel information*

The interventions discussed in this section would all help in various ways to help travellers with mental impairments in making journeys, particularly to increase confidence in making a journey, as shown in Table 31.

Inclusive travel guides provide explanations about the various steps in making a journey, particularly those involving interactions with members of staff and how to obtain information. Similarly pre-travel information through websites and leaflets presented in formats that people with mental impairments can comprehend, will help some people. While not all people with mental impairments need information to be presented in simplified formats, there are many who would benefit. Clear signs would help to simplify the journey by assisting in decision making by providing information in appropriate ways.

Audio-visual information has been provided on some buses and trains for a number of years. It can increase information for people with cognitive impairments by reinforcing the message about the next stop and the route of the bus or train. This can reduce the need to rely on memory and make decision making easier.

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<sup>242</sup> The Institution of Engineering and Technology and ITS-UK, **Meeting the Needs of Older and Disabled Travellers** (2015), available from <http://www.theiet.org/factfiles/transport/age-pop-page.cfm?type=pdf>.

Mobile phone apps have huge potential to assist people with cognitive impairments to travel by providing information tailored to the needs of the individual and the specific journey that he or she is making. The enables the user to request assistance from a carer or a public transport staff member, enables carers to track where the traveller is and can alert a carer or staff member when the person leaves the planned route. A number of wayfinding and public transport apps have been developed but most of them are not appropriate for people with mental impairments, although it is possible that some of them could be adapted. The main difficulty is ensuring that the apps that are being developed do actually meet the needs of people with cognitive impairments. There needs to be interaction between the potential users of the apps and the developers at the design stage, and then thorough evaluation of the effectiveness of the app, with feedback into the design process. Otherwise there is a danger that apps will be developed that may be of some value to people with mental impairments but that do not meet their full potential.

Table 31 The mental skills used in travel that may be enhanced by providing clear information

	Ability to remember	Comprehension	Decision making	Interpersonal communication	Confidence in travelling alone	Ability to behave appropriately
Inclusive travel guides		•	•		•	
Pre-travel information	•	•	•		•	
Clear signs	•	•	•		•	
Audio-visual information	•		•		•	
Mobile phone apps	•		•	•	•	

## 5.5 Interventions to provide support on the journey

### 5.5.1 Staff training

Staff training especially for bus drivers can help to reduce communication difficulties for people with mental impairments. The European Union has required mandatory disability awareness training for bus and coach drivers. The United Kingdom chose to be exempt under EU Regulation 181/2011 (concerning bus and coach passenger rights), but it is now planning to change this.

Some schemes include training about assisting people with mental impairments<sup>243</sup>. This can include awareness of hidden disabilities, training in how to talk to people with mental health issues and cognitive impairments, awareness and understanding of their needs and ways of

<sup>243</sup> Department for Transport, **Summary of responses to the Department for Transport's review of the mandatory disability awareness training exemption applied under EU Regulation 181/2011 (concerning bus and coach passenger rights)** (2015), available from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/398693/summary-responses-2a.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398693/summary-responses-2a.pdf).

presenting information in appropriate ways. For example, in Northumberland a dementia awareness training package for local bus drivers has been developed for inclusion in the Certificate of Professional Competency, with assistance from members of the Northumberland Dementia Forums<sup>244</sup>. First Group runs four training modules that contain disability awareness content, one of which is 'Better Journeys for Life - Playing our Part' which includes an introduction to dementia and other unseen mental illnesses and information about how drivers can assist these customers<sup>245</sup>. Other bus operators that include dementia awareness training for their drivers include TrentBarton, East Yorkshire Motor Services and Blackpool Transport.

The Passenger Assistant Training Scheme (PATS)<sup>246</sup>, developed jointly by the Community Transport Association and Hampshire County Council, provides a nationally recognised standard of training to people whose role it is to provide care and assistance to passengers travelling by on community transport. It includes five modules: a foundation one for all passenger assistants and four others depending on the needs of the people being carried. The module on 'Supervising children and young people with special needs' includes training about assisting people with learning disabilities, autism, and emotional or behavioural difficulties while the module entitled 'Working with adults who require care and supervision' includes learning difficulties, dementia and people in mental or emotional distress.

There may be a case for some staff, for example at large railway stations, to acquire particular skills such as learning Makaton<sup>247</sup>. Makaton is a language programme using signs and symbols to help people to communicate which was developed for those who struggle to understand the spoken word, such as people with profound learning disabilities.

Training of taxi drivers to help people with mental impairments should include escorting people safely to the door at the destination, waiting until after the door bell has been rung and offering a courtesy call before arriving to collect the person to say that the taxi is approaching and before the destination to alert the person's carer or other responsible person that he or she is arriving<sup>248</sup>.

### *5.5.2 Presence of staff*

The presence of staff on vehicles, at stations and at interchanges provides reassurance and information. Hunter-Zaworski and Hron<sup>249</sup> concluded from the surveys that they carried out, that human contact was the most important way of helping a person with cognitive

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<sup>244</sup> North East Dementia Alliance, Drivers for Change: dementia-friendly bus transport in Northumberland, **Joining the Dots, Innovation Funding Grant Holders 2013**, 2-3, available from <http://www.nr-foundation.org.uk/downloads/DFC-organisations-March-26-2013.pdf>.

<sup>245</sup> See note 243.

<sup>246</sup> Community Transport Association, PATS (Passenger Assistant Training Scheme) available from <http://www.ctauk.org/training/pats.aspx>.

<sup>247</sup> Makaton Charity, **About Makaton**, available from <https://www.makaton.org/aboutMakaton/>.

<sup>248</sup> See note 73.

<sup>249</sup> See note 8.

impairments, and that technology was not rated as a useful substitute for human contact. Having staff available was also very useful for defusing inappropriate situations. They concluded that staff training should include ensuring that staff are comfortable serving people with cognitive disabilities and know how to offer appropriate help.

### 5.5.3 Passenger assistance schemes

Passenger assistance schemes involve the provision of assistance to disabled people who request it, often in advance, for example, at railway stations. In Britain it is possible for anyone who requests assistance to book it<sup>250</sup>. The on-line form includes learning disability as one of the categories of impairment but this is the only mental impairment mentioned explicitly.

Passenger Focus<sup>251</sup> carried out a survey into the effectiveness of the Passenger Assist scheme on the railways. The survey showed that people with hidden disabilities found it far more difficult to negotiate their way around the railway as customer-facing staff sometimes failed to understand their needs and requirements. Some staff judged these users as not requiring help or questioned their entitlement to it. Three quotes from people with cognitive impairments illustrate the issues:

- *“I had to ask station staff to help me and show me to my seat. It was a bit awkward to have to ask him to help me. He didn’t tell me what he was going to do and I need to be told as it helps me to understand.”*
- *“It would be nice if staff had some understanding about what people of my condition need. It’s the lack of communication that upsets me or leaves me feeling nervous.”*
- *“I don’t think he understood what I needed. I had to think about my situation and what I thought I needed and he told me they only cater for mobility issues. I told him I used a similar system at the airport and they used a wheelchair and he said, ‘okay we’ll use a wheelchair’ [at the station].”*

Rica<sup>252</sup> carried out a survey on Passenger Assist by following 51 disabled passengers with booked assistance, who were expected to each complete 10 journeys in the year from April 2014 to March 2015. A diary was kept for each trip. Of the 51, 8 had learning disabilities and one had behavioural (ASD) difficulties. 474 journeys were made during the year. Of these, 21 were by people with a learning disability. Trips by people with learning disabilities showed lower satisfaction levels than trips by people with other disabilities. Fewer of the people with a learning disability rated the assistance received ‘very good’ than any other disability, and fewer felt very confident.

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<sup>250</sup> ATOC, **Travel Assistance**, available from <http://www.disabledpersons-railcard.co.uk/travel-assistance/>.

<sup>251</sup> Passenger Focus, **Passenger Assist Summary Report** (2014), available from <http://www.passengerfocus.org.uk/research/publications/passenger-assist-summary-report>.

<sup>252</sup> Rica, **Rica Passenger Assist Longitudinal Study – Year 1 Report** (2015), available from <http://www.vision2020uk.org.uk/wp-content/uploads/Rica-Passenger-Assist-Longitudinal-Study-Year-1-Summary-Final.pdf>.

This illustrates the need for adequate staff training including understanding the needs of people with mental impairments and showing them respect.

#### *5.5.4 Travel assistance cards*

A number of transport operators and PTEs issue Travel (or Journey) Assistance (or Support) Cards which users can show to staff to indicate their disability or particular needs. Some cards have a pre-printed messages such as 'I have a hidden disability' while others have a blank space for the user to write in his or her specific message to the bus driver.

For example, Transport for London<sup>253</sup> issues a 'Travel Support card' which allows the user to write in the type of support that they require. The Passenger Transport Executives (PTEs) in the other conurbations in England all issue such cards. The scheme is being supported by the Confederation of Passenger Transport<sup>254</sup> (CPT) which provides model examples of the card for operators to issue. A number of messages which may be useful to people with hidden impairments are available including:

- Please be patient: I have a hidden disability;
- Please scan my pass for me;
- Please count my change for me;
- Please help me find a seat;
- Driver, please let me know when we get to...'
- Please tell me when we reach my stop...

Some, at least, of the bus companies which are members of the CPT issue the cards, for example, Arriva<sup>255</sup>. The cards are part of the CPT's Code to Assist Passengers with Hidden Disabilities. One objective of the code is to ensure that the passenger knows that if they carry a Journey Assistance Card that it will be accepted and that they will receive assistance from all drivers, regardless of the operator or the bus service. This is necessary because the body issuing a card usually puts its logo on it and it is important that both the passenger and the driver realise that a card carrying the logo of one operator will be accepted on the buses of other operators.

#### *5.5.5 Safe Places*

Safe Places schemes involve the person carrying a card stating their carer's contact details, and local shops and services carrying the Safe Places logo and having trained staff. A cardholder with difficulties can ask the member of staff to contact their carer and wait while

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<sup>253</sup> Transport for London, **How to Use your Travel Support Card**, available from <http://content.tfl.gov.uk/using-a-travel-support-card.pdf>.

<sup>254</sup> Confederation of Passenger Transport, **Journey Assistance Cards: A Passenger's Guide** (2014), available from [http://www.cpt-uk.org//\\_uploads/attachment/2930.pdf](http://www.cpt-uk.org//_uploads/attachment/2930.pdf).

<sup>255</sup> Arriva, **How to Obtain Assistance Cards**, available from <https://www.arrivabus.co.uk/travel-help-and-accessibility/how-to-obtain-assistance-cards/>.

he or she comes to collect them, if that is their desired course of action. Safe Places Organisation CIC<sup>256</sup> is an umbrella organisation for local schemes.

An example is the Bradford Safe Place Scheme<sup>257</sup> which uses the 'Help I'm Lost Cards'. The card contains the message *"I have a learning and a communication difficulty. I may not be able to understand your questions and be able to make myself understood"* on the front. On the back it says: *"I am lost. Can you help me please? My name is ..... Can you please ring ....."*. Shops participating in the scheme display the Safe Places symbol. Police, uniformed security staff and station staff are trained to understand what the cards mean and what they are expected to do to provide assistance.

Avon and Somerset Constabulary<sup>258</sup> operate a similar scheme in Bristol. The same sticker is used in shops as in Bradford. Staff at Safe Place locations are given the following advice<sup>259</sup>:

- Is there an emergency? In an emergency situation, such as when someone requires urgent medical attention or when there is a crime in progress, call 999; to report a crime when the situation is no longer urgent, call 101;
- Offer Reassurance: make sure the person knows you are happy to support them;
- Tell the person your name and your role, so they know who you are;
- Avoid physical contact as some people may react in unexpected ways
- Speak slowly and clearly as this gives the person the best chance to understand what you are saying;
- Ask for their 'I Need Help Card' and call their contact person if necessary and ask for them to come as soon as possible;
- Provide support and advice: this may be giving directions or bus details but could be more serious and they may require support if they are being bullied or harassed;
- Stay with the person if possible, until their named person or emergency services arrives;
- Fill in your Safe Places Log: please now complete a record of this incident.

This initiative requires two key inputs: a local body to take the initiative to set the scheme up, and local shops and offices willing to participate by designating members of staff to provide the assistance. Schemes have been set up in various parts of the country, but they do not seem to exist everywhere.

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<sup>256</sup> Safe Places Organisation CIC, **What are Safe Places?** available from <http://www.safeplaces.org.uk/>

<sup>257</sup> SNOOP, **Help I'm Lost Cards: the Bradford Safe Place Scheme**, Special Needs Objective Outreach Project, available from <http://www.snoopcharity.org/portfolio-view/help-im-lost-cards-2/>.

<sup>258</sup> Avon and Somerset Constabulary, **Safe Places Scheme**, available from <https://www.avonandsomerset.police.uk/safeplaces>.

<sup>259</sup> Avon and Somerset Constabulary, **Advice Guide for Safe Place Locations**, available from <https://www.avonandsomerset.police.uk/media/52058/advice-guide-for-safe-place-locations.pdf>.

### *5.5.6 Tracking people with dementia*

The Herbert Protocol is a national scheme that encourages carers of people with dementia to complete a form containing essential information about the person that they look after so that the information can be used if they go missing. The form used issued by West Yorkshire Police<sup>260</sup>, for example, includes a description of the person, contact numbers, previous addresses, weekly habits and routines and a recent photograph, plus information completed at the time when the person goes missing about how they are dressed, when and where they were last seen and any risk factors. In the event of the person going missing, the form can be given to the police so they do not need to gather this information, which can speed up the investigation time. The Herbert Protocol initiative is named after George Herbert, a War veteran of the Normandy landings, who lived with dementia. The initiative is implemented through individual police forces, and so relies on local initiatives. It requires little in the way of resources, just a form on a website, plus suitable publicity. It may save resources if it enables a lost person to be found quickly.

In London, Oyster card numbers can be registered so that the person can be tracked if they use public transport<sup>261</sup>.

### *5.5.7 Better understanding from the public*

The issue of poor attitudes and behaviour is much wider than the transport field, but travelling is an area where strangers need to mix together and sometimes need to co-operate so there needs to be tolerance of people whose behaviour seems to be unusual.

People with mental impairments suffer from more discrimination and prejudice than people with physical and sensory impairments, as discussed in Section 4.1<sup>262</sup>. They are also more likely to have been victims of hate crime. A significant effect of such crime is a loss of confidence and an increased feeling of vulnerability.

Table 13 showed that more people with mental impairments using the bus found the behaviour of other passengers a concern than either people with no impairment or people with other types of impairment. As discussed in Section 4.3, the behaviour of other passengers that caused concern for people with learning disabilities included smoking, drug taking, playing loud music, bullying and large groups of children shouting and banging on the buses. The attitudes of other passengers was identified as a factor that discouraged people with intellectual impairments from using local buses in Table 11.

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<sup>260</sup> West Yorkshire Police, The Herbert Protocol, Safe and Found, available at <https://www.westyorkshire.police.uk/dementia/herbert-protocol>.

<sup>261</sup> See note 73.

<sup>262</sup> See note 2.

Transport for London (TfL)<sup>263</sup> conducted qualitative research in Autumn 2015 which included 16 accompanied travel interviews with people with hidden disabilities or conditions, and group discussions with general customers and TfL staff. The research showed that the public perceive the entitlement to priority seating is based on visible conditions with older people and pregnant women being seen as being in more need than those with hidden disabilities such as mental impairments. TfL then conducted a trial of the 'Please offer me a seat' badge for those with a hidden disability designed to alert fellow passengers of their need for a seat on public transport. 1,000 people were recruited to take part in a six-week trial starting in September 2016 to assess how successful it was for passengers to use and the reactions of others. They were also given a card that could be shown to TfL staff.

It would be challenging to change the attitudes and behaviour of the public towards people with mental impairments. Anecdotal evidence suggests that the Paralympic Games in London in 2012 improved attitudes towards people with physical impairments, but it is not clear that this effect, if it were the case, extended to those with mental impairments.

It can be argued that there has been a reduction in racial discrimination over the past fifty years through legislation and education. The same legislation covers discrimination on the grounds of race and disability, namely the Equality Act 2010. With active support from government at all levels, more positive role models in the media and prosecution of those who break the law by discriminating against disabled people, it should be possible to make a difference for people with mental impairments. The inclusion of some children with mental impairments in mainstream education probably helps since it makes other children aware that there are other people around who need extra assistance. Whilst anti-stigma campaigns would cost money, if they enable some people with mental impairments to be employed it might well be cost effective as well as morally right<sup>264</sup>.

#### *5.5.8 The effects of interventions to provide support on the journey*

The interventions described in this section would all help to increase the confidence of people with mental impairments to travel, as indicated in Table 32. Staff training, the presence of staff during the journey, passenger assistance schemes and travel assistance cards would all help by increasing the support from trained staff during the course of the journey and providing reassurance. Safe Place schemes and tracking people with dementia provide reassurance for travellers with mental impairments and their carers by offering the opportunity to seek assistance and a way of contacting a carer if necessary. Better understanding from the public of the needs of people with mental impairments should

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<sup>263</sup> Transport for London, **Please offer me a seat - new badge created for those less able to stand**, available from <https://tfl.gov.uk/info-for/media/press-releases/2016/august/please-offer-me-a-seat--new-badge-created-for-those-less-able-to-stand>.

<sup>264</sup> Department of Health, **No Health without Mental Health: A cross- Government mental health outcomes strategy for people of all ages: Supporting document – The economic case for improving efficiency and quality in mental health** (2011), available from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215808/dh\\_123993.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215808/dh_123993.pdf).

increase the number of people who are willing to offer assistance and reduce examples of impatience and intolerance if, for example, a person with a mental impairment appears to be slow or behaving unusually.

Table 32 The mental skills used in travel that may be enhanced by providing support during the journey

	Ability to remember	Comprehension	Decision making	Interpersonal communication	Confidence in travelling alone	Ability to behave appropriately
Staff training				•	•	•
Presence of staff during the journey					•	•
Passenger assistance schemes					•	
Travel assistance cards				•	•	•
Safe Places					•	•
Tracking people					•	
Better understanding from the public				•	•	•

## 5.6 Interventions to make travel cheaper

### 5.6.1 Reduced price car lease

Schemes such as Motability<sup>265</sup> enable disabled people to lease a car at a reduced price assisting some people with, for example, mental health conditions such as agoraphobia, who could not otherwise afford to do so, to drive, for example, to work. The scheme allows disabled people to lease a car, a Wheelchair Accessible Vehicle (WAV), a scooter or powered wheelchair, whichever suits their needs best, with insurance, maintenance and breakdown included in the price. The standard lease length is three years and relevant payments are deducted from the user's mobility allowance every four weeks, and paid directly to Motability by the Department for Work and Pensions. In the case of a car, the user just pays for fuel. At the end of the lease, the user hands the car back and can then select a new car and take another lease.

People who are eligible for the Motability scheme are those in receipt of the Higher Rate Mobility Component of the Disability Living Allowance (HRMC of DLA), the Enhanced Rate of the Mobility Component of Personal Independence Payment (ERMC of PIP) or certain allowances associated with having been in the armed forces. These are the same as the Type 1 eligibility criteria for a Blue Badge for parking. The same issue arises for people of working

<sup>265</sup> Motability, *Your Guide to Leasing a Motability Car* (2016), available from <http://www.days.co.uk/Motability%20your%20Guide.pdf>.

age who have switched from receiving DLA to receiving PIP. Many people who previously leased a car under the Motability scheme can no longer do so. Motability provides some transitional support for those who are no longer eligible to lease a car under the scheme including allowing customers to retain their vehicle for up to three weeks after DLA payments end and providing a lump sum payment to those who return their cars in a good condition<sup>266</sup>.

### 5.6.2 Free or reduced price public transport

In Britain, disabled people are entitled to free off-peak travel on buses and are able to purchase a card offering a discount on rail travel. This is important because many disabled people have low incomes because their impairment limits their opportunity to be employed. For people with mental impairments, the use of the concessionary bus pass removes the need to communicate verbally with the bus driver and to handle money which could make bus travelling much easier for some of them. It can also reduce anxiety associated with being on the wrong bus. However, SYSTRA<sup>267</sup>, in its discussions with people with learning disabilities in the West Midlands, found that some of them were anxious about understanding the rules under which they could use the pass.

Free off-peak bus travel for disabled people in England is provided under the English National Concessionary Travel Scheme (ENCTS) under the provisions of Section 146 of the Transport Act 2000<sup>268</sup>. Equivalent schemes exist in Scotland, Wales and Northern Ireland. People in receipt of the higher rate DLA mobility component, and those receiving PIP who have been awarded at least 8 points against either the PIP 'Moving around' and/or 'Communicating verbally' activities, plus people in receipt of certain allowances resulting from being in the armed forces are eligible (the same as for Blue Badges and Motability). In addition, people with certain specified disabilities are eligible. These include having a learning disability, that is, a state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning, or, if he or she applied for a licence to drive a motor vehicle and had his or her application refused on the grounds of physical fitness. The Guidance on assessing eligibility on the grounds of disability issued to local authorities by the Department for Transport<sup>269</sup> includes 'severe mental disorder' under this heading. In paragraph 58 it explains: *"There are a number of categories of 'severe mental disorder' under which people may qualify. Authorities will need to assess individuals on a case-by-case basis as eligibility may depend on the severity of the condition. Such conditions include (but are not limited to) dementia (or any organic brain syndrome); behaviour disorders (including post*

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<sup>266</sup> Motability, **Unsuccessful PIP reassessment**, available from <http://www.motability.co.uk/about-the-scheme/unsuccessful-reassessment/>.

<sup>267</sup> See note 97.

<sup>268</sup> Butcher L, **Concessionary Bus Fares**, Commons Briefing papers SN01499 (2015), available from <http://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN01499#fullreport>.

<sup>269</sup> Department for Transport, **Guidance to Local Authorities on Assessing Eligibility of Disabled People in England for Concessionary Bus Travel** (2013), available from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/181507/eligibility-review.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/181507/eligibility-review.pdf).

*head injury syndrome and Non-Epileptic Seizure Disorder*); and *personality disorders*". The mental impairments that the DVLA must be informed about which might lead to the refusal of a driving licence are shown in Table 26. The Guidance states that it is not necessary for a disabled person to actually apply for and be refused a driving licence. If, for people with some disabilities including a 'severe mental disorder', the local authority can be confident that a driving licence would be refused, it should issue the travel pass automatically.

Bus passes are issued under ENCTS by local authorities who have to decide whether an applicant is eligible. This raises a number of issues for people with mental impairments. Firstly, different interpretations of eligibility may be made by different local authorities, so that two people with the same health condition but living in different areas, may be treated differently. Secondly, some people with mental impairments may not realise that they are eligible. For example, in the survey carried out by the Mental Health Action Group<sup>270</sup> it was found that a number of people with mental health conditions did not realise that they might be eligible for a bus pass.

Some local authorities offer extra local concessions, for which they provide the funding. For example, in West Yorkshire and Hertfordshire it is possible to obtain a discretionary companion permit if an ENCTS permit holder cannot always travel unassisted, and they meet qualifying criteria<sup>271 272</sup>. The companion permit allows one other person to travel for free on buses (within the local authority boundary) with the ENCTS permit holder. They do not always have to travel with a companion and it does not have to be the same companion who always travels with them. Some people with mental impairments would probably be eligible for this extra concession.

The ENCTS allows free bus travel between 9.30 am and 11.00 pm on weekdays, as well as free travel at weekends and bank holidays. A local discretionary concessionary available in some areas such as London and Hertfordshire is being able to travel at any time of day but this has to be funded by the local transport authority. In West Yorkshire feedback has been received particularly for people with a learning disability that they would like to see their ENCTS permit to cover free travel before 9.30 am<sup>273</sup>. This is to give them access to education or to voluntary, low paid or part time work. In these instances it is not always an option to choose to travel after 9.30 am.

Providing a pass enabling free bus travel may even help with some mental health conditions. In their study in the Gospel Oak neighbourhood in North London where half the participants had a common mental disorder, Whitley and Prince<sup>274</sup> found that, for residents with this

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<sup>270</sup> See note 77.

<sup>271</sup> Metro, **Blind & Disabled Pass Benefits**, available at [https://ticketsandpasses.wymetro.com/Benefits\\_-\\_what\\_do\\_i\\_get/](https://ticketsandpasses.wymetro.com/Benefits_-_what_do_i_get/).

<sup>272</sup> Hertfordshire County Council, **The Companion Pass**, available from [http://www.hertfordshire.gov.uk/images/icon/h/Companion\\_pass.pdf](http://www.hertfordshire.gov.uk/images/icon/h/Companion_pass.pdf).

<sup>273</sup> Ward E (West Yorkshire Combined Authority), Individual communication to author 24 February 2015.

<sup>274</sup> See note 82.

condition, which was one characterised by anxiety and depressive symptoms, the Freedom Pass, the equivalent to ENCTS in London, allowed them to access services, facilities and social support outside the neighbourhood which appeared to ameliorate some of the symptoms of their condition and prevent deterioration.

Train Operating Companies (TOCs) are required under the terms of their franchise agreements to participate in approved discount card schemes for certain groups including disabled passengers under Section 28(3) of the Railways Act 1993<sup>275</sup>. Those who are eligible receive a discount of one third off adult rail fares for travel on the National Rail network in Great Britain. If they are travelling with another adult he or she also receives one third off their rail fare. There are no time restrictions on the Disabled Persons Railcard. Eligibility includes receiving Personal Independence Payments (PIP) (at any level) or receiving Disability Living Allowance (DLA) at either the higher or lower rate for the mobility component, or the higher or middle rate for the care component. These are the most likely grounds on which a person with a mental impairment could obtain a Disabled Persons Railcard. It should be noted that the requirements based on PIP are less stringent than those for a Blue Badge for parking or Motability.

### 5.6.3 *The effects of interventions to make travel cheaper*

Reduced price car lease can assist people with mental impairments such as agoraphobia travel by car and avoid walking long distances. Free bus travel can assist by removing the need to handle money to pay for travel and can simplify interactions with staff such as bus drivers. Free or reduced price travel and reduced price car lease can also overcome the barrier of cost which prevents some people with mental impairments from travelling as discussed in Section 4 as some of them have limited incomes resulting from their inability to carry out highly paid employment.

Table 33 indicates how these interventions may help with addressing the lack of mental skills used in making a journey.

Table 33 The mental skills used in travel that may be enhanced by making travel cheaper

	<b>Ability to remember</b>	<b>Compre- hension</b>	<b>Decision making</b>	<b>Interpersonal communi- cation</b>	<b>Confidence in travelling alone</b>	<b>Ability to behave appropriately</b>
Reduced price car lease					•	•
Free or reduced price travel					•	

<sup>275</sup> Butcher L, **Rail Fares and Ticketing**, Commons Briefing papers SN01904 (2016), available from <http://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN01904>.

## 5.7 Comprehensive packages of measures

### 5.7.1 Personalised travel planning

Personalised travel planning involves the provision of information tailored to the travel needs of an individual or household, based on a study of their existing trip patterns and discussion about their travel needs. It helps to overcome the issue that many people are not aware of the alternatives to their existing trips or have misperceptions, for example, about bus fares or frequencies. The technique may also be very useful for groups of people with a common origin or destination in order to match the provision of transport to both their common and individual needs.

A good example<sup>276</sup> is the a study of a multi-purpose day centre in Goole attended by people with learning disabilities in which the individual travel needs of those attending it were examined. The study led to the replacement of the use of a council minibus by other more cost-effective means tailored to the requirements of the people involved such as people being brought to the centre by a relative whose costs were paid and three people who share a taxi, giving them greater flexibility. A second example was in Sheffield where six people were living together in three adjoining houses supported by a voluntary organisation. They switched from using the council minibus to leasing a car driven by the support workers at the house. This meant they spent less time travelling and that they could make spontaneous trips using the car.

The process that was gone through was to work out the journeys that each person wished to make over a period in a diary; this was then costed using the person's preferred means of travel. This was checked against the person's budget. If the budget was exceeded then some journeys had to be removed or made in cheaper (but still acceptable) ways of travelling. Then the possible risks and ways of enabling the person concerned to cope with them were identified, not necessarily avoiding the risks just because carers and support workers thought it was too risky. Then a pilot study was carried out with a group of suitable people and the results documented, both positive and negative.

### 5.7.2 Dementia-friendly communities

It is possible to make whole areas accessible for people for people with mental impairments. A good example is making cities dementia-friendly, such as York, which means that people with dementia are able to travel with greater confidence. In a project examining dementia-friendly York<sup>277</sup>, people with dementia and their families said that they would travel further if necessary to do their shopping where they were certain of friendly staff who would provide the necessary advice and help, where parking was straightforward and where the layout of the store made it easy to find the way around. As well as undertaking the supported journeys

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<sup>276</sup> Inclusion North, **Personalising Travel for People with Learning Disabilities: Toolkit for making change happen**, prepared by M Bukowski and R Armitage (2011), available from <http://inclusionnorth.org/uploads/attachment/289/personalisation-travel-toolkit.pdf>.

<sup>277</sup> Crampton J, Dean J and Eley R, **Creating a Dementia-Friendly York**, Joseph Rowntree Foundation (2012), available from <http://www.jrf.org.uk/publications/creating-dementia-friendly-york>.

discussed above in Section 5.2.2, train companies serving York now include dementia awareness at their staff briefing sessions and staff at major stations in north east England have undergone the 'Dementia Friends' programme<sup>278</sup>. As a result of the training, customer-facing staff take disoriented passengers to a quiet area where they are given time and space to relax and receive support to enable them to continue their journey. The champion from the British Transport Police has worked with relevant local groups and networks including the local Dementia Action Alliance to discuss and identify local priorities, including the 'Dementia without walls' working group coordinated by the Joseph Rowntree Foundation. In the report on dementia-friendly York<sup>279</sup> it says that people with dementia found the local bus service useful but that the numbering and colour coding of the services was confusing. An important issue when away from home is being able to access easy-to-use toilet facilities: this means the introduction of family-friendly toilets with only one exit which can be observed from a distance, to address the concern that a person with dementia may take the wrong exit and become lost.

In March 2012 David Cameron, the then prime minister, launched a national challenge to fight dementia which was a programme of action to deliver sustained improvements in health and care, create dementia-friendly communities, and to boost dementia research<sup>280</sup>.

The British Standards Institute<sup>281</sup> in co-operation with the Alzheimer's Society has produced a code of practice for the recognition of dementia-friendly communities in England. The document provides detailed guidance for communities by explaining what a dementia-friendly community looks like and outlining the key areas for action required to achieve a dementia-friendly community. The code provides recommendations on:

- Who needs to be involved in setting up a dementia-friendly community;
- Aims that should be central to all dementia-friendly communities;
- Areas for action to focus on and the processes needed for a dementia-friendly community to operate successfully;
- The positive changes for people with dementia that would be expected to be seen in a dementia-friendly community.

The Alzheimer's Society has outlined the foundation criteria for recognition as a dementia-friendly community<sup>282</sup>. These are:

- Making sure that there is the right local structure in place to maintain a sustainable dementia-friendly community;

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<sup>278</sup> See note 194.

<sup>279</sup> See note 277.

<sup>280</sup> Department of Health, **Prime Minister's Challenge on Dementia 2020** (2015), available from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/414344/pm-dementia2020.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf).

<sup>281</sup> British Standards Institute, **Code of Practice for the Recognition of Dementia-Friendly Communities in England**, PAS 1365:2015 (2015), available from <http://shop.bsigroup.com/forms/PASs/PAS-1365-2015/>.

<sup>282</sup> Alzheimer's Society, **Foundation Criteria for the Recognition Process** (2014), available from [https://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=2886](https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2886).

- Identification of a person or people to take responsibility for driving forward the work to support the community to become dementia-friendly and ensuring that individuals, organisations and businesses are meeting their stated commitments;
- Having a plan to raise awareness about dementia in key organisations and businesses within the community that support people with dementia;
- Developing a strong voice for people with dementia living in the community which gives the plan credibility and ensures that it focuses on areas which people with dementia feel are most important;
- Raising the profile of the work to increase reach and awareness to different groups in the community;
- Focusing the plans on a number of key areas that have been identified locally;
- Having in place a plan or system to update the progress of the community after six months and one year.

The following aspects of local transport in the area are required<sup>283</sup>:

- Customer-facing employees should be trained to be dementia-friendly;
- People with dementia should be encouraged to carry assistance cards, identification and their carer's emergency contact details;
- Seating and shelter should be provided at major stops and stations;
- Where supporting technology is available, there should be appropriate audio-visual announcements of stops;
- Signage should be clearly visible and understandable;
- Maps and guides should be easy to read and navigate;
- Alternatives to bus and train transport should be provided in all areas, including areas where public transport services do not exist; the following should be considered:
  - volunteers as drivers;
  - dementia-friendly taxi services; this may include the taxi driver knocking on the door and assisting the person with dementia at their destination with finding the correct address rather than dropping them outside; a dementia-friendly taxi company may assign the same drivers to their regular customers with dementia.

A useful toolkit to help local authorities to develop dementia friendly communities has been produced by Alzheimer's Australia<sup>284</sup>. This suggests three steps to creating a dementia-friendly community:

- **Create a climate for change** by identifying a champion, reviewing existing policies and frameworks, starting a conversation on the topic within the local authority, and considering the benefits of being proactive in the short-term and how measures can be embedded into the long-term planning process;

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<sup>283</sup> See note 281.

<sup>284</sup> Alzheimer's Australia, **Creating Dementia-Friendly Communities: A Toolkit for Local Government** (2016), available from <https://www.fightdementia.org.au/files/NATIONAL/documents/Dementia-friendly-communities-toolkit-for-local-government.pdf>.

- **Engage with colleagues and the community** by engaging with others in the local authority and the wider community, talking to people with dementia and their carers and families about what is important to them and seeking support from a relevant outside organization such as the Alzheimer’s Society;
- **Implement and sustain change** by taking some action, for example, creating a local dementia alliance within the local authority and the community, and developing some achievable action items within a dementia action plan.

### 5.7.3 Local packages

Comprehensive packages such as that being considered by Transport for West Midlands (TfWM)<sup>285</sup> bring together a number of the measures being discussed above for the West Midlands. The package of 4 initiatives is collectively branded as ‘MobilitySmart’:

- MobilityPass is the new brand name for the local concessionary travel pass which enables local residents to use the buses under the ENCTS scheme but also local rail and the Metro light rail system between Wolverhampton and Birmingham;
- MobilityAssist is a series of initiatives to assist people who are not used to using public transport to do so; it includes:
  - Travel training;
  - Travel Buddy service;
  - Technology support to help people to use tools such as on-line journey planning, apps, etc.;
  - A training module on accessing public transport information to sit within e-learning training packages;
  - Mobility days;
  - Mobility champions;
  - ‘Be Safe on the Network’: dedicated safety talks by the Safer Travel Team.
- Flexilink which is a new local bus service from residential areas to local supermarkets and shopping centres open to everyone using small step-free vehicles which can be booked in advance like Dial-a-Ride but which will operate along a fixed route.
- MobilityChoice: this would give customers a financially capped annual personal mobility purse to fund the use on any door-to-door journey they wish to take in the West Midlands with the customer meeting the balance of the cost. Services could be provided by community transport operators, taxi and private hire companies who meet the specification for accessibility and customer service for door-to-door services under a Quality Framework involving transport operators. This could serve people with mental impairments providing that appropriate training and safeguards are in place.

Whilst the package is not aimed specifically aimed at people with mental impairments, it includes a number of the interventions discussed above, and so could prove to be very useful.

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<sup>285</sup> See note 215.

#### 5.7.4 The effects of comprehensive packages of measures

The packages discussed in this section bring together some of the interventions discussed elsewhere, and so they help to supplement the skills that people with mental impairments have in order to assist them in travelling, as indicated in Table 34.

Table 34 The mental skills used in travel that may be enhanced by the introduction of comprehensive packages of measures

	Ability to remember	Comprehension	Decision making	Interpersonal communication	Confidence in travelling alone	Ability to behave appropriately
Personalised travel planning		•	•		•	
Dementia-friendly communities	•	•	•	•	•	
Local packages	•	•	•	•	•	

## 6 Conclusions

The Equality Act 2010 was passed by the UK Government to reduce socio-equalities and to eliminate discrimination, including on the grounds of disability, both physical and mental, when the person's impairment has a substantial and long-term adverse impact on everyday activities including travelling<sup>286</sup>. This report has concentrated on mental impairments, as experienced by, for example, people with learning disabilities, people with dementia and people with mental health issues. The purpose of this report was to examine the evidence about travel by people with mental impairments. It has done so by considering the mental skills that are used in travelling, how conventional transport systems create barriers for people with mental impairments and how interventions can be used to improve accessibility for people with mental impairments by overcoming the barriers.

From a number of papers that examine the mental aspects of making a journey discussed in Section 2<sup>287</sup>, plus observation, the following mental skills can be identified as being required to make a journey:

- **The ability to remember:** travelling requires the recall of information obtained previously, for example the route to the bus stop, which bus to catch and the final destination;
- **Comprehension:** the ability to understand information from explicit sources such as direction signs, electronic screens and people, by interpreting the landscape, such as landmarks, and intuitively such as having a sense of direction;
- **Decision making:** the ability to process information and to make decisions based on it, for example, whether to turn left or right, deciding when to indicate to the driver to stop the bus and deciding how much time to allow for interchange;

<sup>286</sup> See notes 1 and 3.

<sup>287</sup> See notes 5-11.

- **Interpersonal communication skills:** the ability to understand others and convey information to them, for example, buying a ticket, asking for assistance and understanding requests from other passengers;
- **Having the confidence to travel alone:** having the self-confidence to obtain enough information and process it to reach the destination efficiently and knowing how to cope if things go wrong;
- **The ability to behave appropriately** in line with the contemporary norms expected by society for a person of the age of the traveller.

There may be a difference in the mental skills required between making a familiar journey and an unfamiliar one. Some of the skills relate to following a route by taking decisions based on information either remembered from a previous journey or observed from signposts, maps and interpreting the landscape, while others relate to interactions with other people during the course of a journey, either to seek information or simply as fellow travellers. The skills are used at various stages in making a journey as shown in Section 2.

The Office for National Statistics<sup>288</sup> has identified the following categories of mental impairment:

- **Learning or understanding or concentrating**, which include conditions such as dementia, learning disabilities, dyslexia, and traumatic brain injuries;
- **Social or behavioural** which include autism, Asperger's syndrome and attention deficit hyperactivity disorder (ADHD);
- **Mental health** which includes conditions such as agoraphobia, anxiety and depression;
- **Memory impairment** which can be associated with conditions such as dementia, traumatic brain injury and a brain tumour.

Some sources of evidence such as the Life Opportunities Survey<sup>289</sup> distinguish between learning impairments, which are conditions acquired at or near birth, such as learning disabilities and dyslexia, and intellectual impairments which are acquired later in life, such as dementia.

A number of mental impairments were discussed in Section 3 including their characteristics and prevalence from sources such as the Health A-Z on the NHS Choices website and the websites of organization that represent the interests of people with these conditions<sup>290</sup>. Some of the impairments exist from birth, some are acquired later in life, and others can fluctuate over time in their effects and may cease. Millions of people in Britain have mental impairments. Some, such as dementia, are expected to increase in number, reaching 2 million by 2051<sup>291</sup>. 26% of all adults in England report having been diagnosed with at least one mental illness. The nature of the condition affects the influence of the mental impairment on the

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<sup>288</sup> See note 14.

<sup>289</sup> See note 60.

<sup>290</sup> See notes 16 to 58.

<sup>291</sup> See note 21.

various mental skills used in travelling and other aspects of everyday life. These impairments affect the mental skills used in travelling in various ways. Many people have more than one impairment, and the impacts on the skills used in travelling vary between individuals both in nature and in severity<sup>292</sup>.

Evidence from surveys and expert knowledge discussed in Section 4.1, showed that there are many factors that make travel challenging for many people with mental impairments and may prevent some of them from going out at all<sup>293</sup>. Evidence from the Life Opportunities Surveys shows that, whilst many people travel less than they wish, for example because of the cost of travel or the lack of availability of transport, people with mental impairments travel even less, in general, as shown in Table 9. This is partly because some of them have difficulty making any journeys because of their condition. In other cases it is due to various factors, as discussed in Sections 4.1 to 4.9. These include:

- **Anxiety**, including concern about overcrowding, concern about personal safety because of the risk of abuse and hate crime and concern about not being able to find a place of safety in an emergency; graffiti and evidence of crime may increase anxiety; other concerns for some people are a fear or embarrassment about falling, and for people with incontinence problems, concern about access to toilet facilities; aggression and anxiety may be exacerbated by being in unfamiliar surroundings which may hinder communication with others;
- **Attitudes of other people**, including intolerance and discrimination by staff and members of the public; because the impairment is hidden the person may not receive the support that they need; the symptoms of some conditions such as dementia may be confused with intoxication;
- **Cost** because many people with mental impairments have low incomes;
- **Inability to drive**;
- **Lack of eligibility** for some special transport services or concessions;
- **Poor spatial awareness** may make wayfinding difficult;
- **Inability to commit** to a journey because of fluctuations in the person's condition;
- **Information** may be poorly presented and not be in a suitable format;
- **Disruption**: some people may have difficulty coping with variation from their routine or what has been learnt on a training course.

Despite the difficulties, travel can be a positive experience for people with mental impairments, for example interactions with staff and other travellers, and the ability to access services and social networks can be therapeutic<sup>294</sup>.

There is some evidence on the difficulties encountered by people with mental impairments when using various modes of transport. For example, as discussed in Section 4.2, when

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<sup>292</sup> See notes 24, 61 and 63.

<sup>293</sup> See notes 65 to 83.

<sup>294</sup> See notes 70, 73 and 82.

walking, people with cognitive functional limitations (CFLs) were found to need to look downwards all the time in order to check the surface, had a fear of walking into people or objects and were concerned that, when crossing the road at pedestrian crossings, the traffic signal would turn red before they had finished crossing<sup>295</sup>. Difficulty crossing the road and distractions when walking were found to be major issues for people on the autistic spectrum<sup>296</sup>. Of the various ways that can be used to follow a chosen route when walking, such as using landmarks or signs, following instructions and using intuition such as a sense of direction, research on people with acquired brain injuries showed that giving directions using landmarks provided the most effective way of providing guidance<sup>297</sup>. Providing a mobile phone was found to be a useful way to provide reassurance and assistance when lost, which was a common concern. The main need seem to be to feel confident when crossing the road and finding the way, with clear, simple route information and a legible landscape with clear landmarks and not too many distractions<sup>298</sup>.

Bus offers the opportunity to travel further than walking and may be the only mode available for some people with mental impairments to make longer trips. Some people are dependent on buses to give them independence to access facilities that they could not do otherwise<sup>299</sup>. Hence, irregular services, delays and long wait times can lead to people missing activities which are very important to them<sup>300</sup>. Lack of a bus service may mean that they have to use taxis in the evening despite the high cost. Use of the bus removes the inconvenience, uncertainty and high cost of parking for some people who might otherwise travel by car<sup>301</sup>.

Evidence has been found on a number of specific issues with bus travel for people with mental impairments from the Life Opportunities Survey<sup>302</sup>, the National Bus Passenger Survey<sup>303</sup>, reports<sup>304</sup> and the academic literature<sup>305</sup> as discussed in Section 4.3:

- **Anxiety and lack of confidence**, which may be partly due the behaviour of drivers and other passengers; drivers are sometimes unhelpful, rude, unable to communicate well, and lacking in knowledge about bus routes and timetables; they do not always stop at bus stops and occasionally take advantage of people with mental impairments; other passengers can cause difficulties such as their behaviour causing stress by smoking, drug taking, playing loud music and bullying, and schoolchildren by being noisy and banging on the side of the bus; people with mental impairments often lack the

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<sup>295</sup> See note 94.

<sup>296</sup> See note 80.

<sup>297</sup> See note 91.

<sup>298</sup> See note 92.

<sup>299</sup> See note 97.

<sup>300</sup> See notes 66, 77 and 97.

<sup>301</sup> See note 97.

<sup>302</sup> See note 89.

<sup>303</sup> See note 103.

<sup>304</sup> See note 77 and 97.

<sup>305</sup> See notes 66, 107, 108 and 112.

confidence to ask fellow passengers for information; overcrowding can cause problems for some people;

- **Cost:** buses can be expensive because many people with mental impairments have low incomes; some people may be assessed as ineligible for a concessionary bus pass, while others may not realise that they are entitled to have one; some of those who do have a concessionary bus pass, may have difficulty understanding the rules, such as where local concessions are available and how to renew the pass.
- **Disruption and change:** when a bus service is disrupted, the lack of an explanation may cause distress; people with mental impairments may lack the ability to generalise about what to do in a novel situation, such as a disrupted journey or a bus terminating short of the advertised destination; when bus routes are revised a person who has had travel training will need to learn about the new routes and this may interfere with knowledge about previously learned routes.
- **Information:** some of the travel information presented may be too complex for some people with mental impairments such as some people with dyslexia.
- **Access:** it may be difficult to get to or from the bus stop because of the need to navigate along the street and cross roads;
- **Children** with conditions such as autism may lack a sense of danger and so may, for example, jump off a moving vehicle; others may find it difficult to switch from one activity to another, such as from sitting on a bus to alighting from it; others may feel a need to always sit in the same seat on the bus and find it difficult if they cannot do so<sup>306</sup>.

The reasons for not using a coach are similar to those for not travelling by bus, but cost is a greater deterrent, as discussed in Section 4.4.

Services such as dial-a-ride can be very useful for people with mental impairments because they can offer a way for some people to make journeys that they may find difficult by conventional buses, but there can be constraints imposed by the timing of services such as finishing part way through the evening and the effects of not crossing local authority boundaries which can prevent some social trips as discussed in Section 4.5<sup>307</sup>. In some places, people with mental impairments may not be eligible to use these services or only be allowed to travel with a carer. In some cases, they may not realise that they are eligible to use the service<sup>308</sup>.

Rail offers the opportunity to make longer journeys by public transport than by bus. Cost is the most critical factor for the overall population but it is an even greater deterrent for people with mental impairments because of their low incomes, as shown in Tables 16 and 17 and discussed in Section 4.6. Anxiety and lack of confidence is another major deterrent for people

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<sup>306</sup> See note 126.

<sup>307</sup> See notes 66 and 97.

<sup>308</sup> See note 73.

with mental impairments. One group that has particular difficulties with rail travel is people with mental health conditions because, for some of them, their condition can fluctuate from day to day, which prevents them from committing to a journey in advance and so they cannot take advantage of cheaper fares that require purchase at least one day in advance<sup>309</sup>. Another issue that affects people with a mental impairment more than other people is concern about personal security. People with mental impairments have a more negative perception of the helpfulness and attitude of station and train staff than both people with no impairments and people with other types of impairment, as shown in Table 21.

Positive aspects of rail travel for some people with mental impairments are the amount of space offered and the availability of toilets on some trains which reduces one aspect of anxiety for some people<sup>310</sup>. However, aspects of the modern design of trains cause problems for some people with mental health conditions, for example, sealed windows in air-conditioned carriages and electronic doors which cannot be opened manually including toilet doors<sup>311</sup>. Operating aspects such as extended periods stationary, especially in tunnels, can also cause distress to some travellers.

Summing up, the key factors affecting rail use by people with mental impairments are:

- Cost;
- Anxiety and lack of confidence;
- Overcrowding;
- Difficulty getting to and from the station;
- Concern about personal security;
- Perceived lack of helpfulness and the attitude of staff on stations and trains;
- For some people with mental health conditions, the need to commit to a journey in advance in order to obtain the cheapest rail tickets.

The factors affecting the use of the London Underground by people with mental impairments are the cost, anxiety and lack of confidence, and overcrowding, plus the fact that, being in London, it is not available to many people, as shown in Table 23 and discussed in Section 4.7. These are similar to the reasons for other people, but the numbers of people affected are greater.

Taxis are a very suitable mode of travel for some people with mental impairments because they convey the traveller from door to door and, if another person makes the booking, gives the driver the location of the destination and makes the payment, require no interaction with any other person. However, as shown in Table 24, some people with mental impairments have anxieties and lack of confidence about using them. Cost is the biggest factor, deterring

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<sup>309</sup> See note 77.

<sup>310</sup> See note 97.

<sup>311</sup> See note 143.

more people with mental impairments than the rest of the population, as discussed in Section 4.8.

There are a number of ways that these issues can be addressed through the interventions discussed in Section 5:

- Enhancing the travel skills of people with mental impairments;
- Reducing the need for travel skills by simplifying travel, by reducing the need to make decisions;
- Increasing the confidence of travellers by providing clear, accessible information at the appropriate time to assist decision making and reducing the risk of information being forgotten;
- Improving the confidence of travellers by providing support from empathetic people during the journey;
- Providing cheaper travel because many people with mental impairments have low incomes.

In general, as shown in Tables 11, 15, 16, 17, and 23, the main barrier to using public transport by people with mental impairments is anxiety and their lack of confidence, reflecting the fact that their impairment adversely affects some of the skills required to travel. Various interventions can be used, either to enhance the travel skills of people with mental impairments, or by modifying the travel environment to reduce the needs for these skills.

One way to enhance people's travel skills is through travel training, as discussed in Section 5.2.1, which can assist with comprehension, decision making and strategies to overcome difficulties recalling information. There are many examples of travel training in Britain, and there have been attempts to ensure best practice is followed, but there is scope for further work in this area. Whilst travel training does seem to be effective in encouraging people with mental impairments to travel and is good value<sup>312</sup> it can be labour intensive, and so can use a lot of resources. Hence there is a need to establish the most effective ways of delivering travel training.

A simpler approach to enhancing travel skills is to offer travel experiences, such as visits to bus stations and organised rail trips for people with mental impairments, as discussed in Section 5.2.2. There are a number of schemes around the country, but often their existence seems to be dependent on initiatives by individuals. Given that such schemes often do not require many resources it seems sensible to encourage them by sharing information about best practice.

One of the best ways to provide support to people with mental impairments when travelling is to provide more staff, for example, on stations, as discussed in Section 5.5.2. Their presence can provide information about how to find the correct train or bus and provide reassurance

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<sup>312</sup> See note 179.

in the case of a sudden need for support. However, it is important that the staff have empathy with people with mental impairments and understand the type assistance that they require. Hence it is very important that staff have received effective training which includes information about the requirements of people with mental impairments and how to communicate with them, as discussed in Section 5.5.1. In Britain, Passenger Assistance on railway stations can be requested by all travellers, as discussed in Section 5.5.3, but there are examples of people with mental impairments being refused assistance by staff because the staff member did not appreciate that the person required assistance because their impairment was not visible. Staff training can address this issue.

One deterrent to travel for people with mental impairments is the attitude and behaviour of other people. Evidence suggests that they suffer more discrimination and prejudice than people with other impairments<sup>313</sup>. There is a need to increase public awareness of the needs of people with mental impairments and to create more awareness of the contribution of people with mental impairments to society. The Equality Act 2010<sup>314</sup> covers a number of personal characteristics for which discrimination has been reduced over time through legislation and campaigns, including race and gender. The same could be applied to discrimination on the grounds of disability, particularly mental impairments. Various initiatives such as TfL's scheme for offering badges to people to people with hidden disabilities requesting a seat on public transport, have great potential, as discussed in Section 5.5.7.

Travel Assistance Cards are an inexpensive way of enabling people with mental impairments to indicate their needs to staff, particularly bus drivers, in a discrete way, as discussed in Section 5.5.4. Whilst they are fairly widely available, they appear in various formats, often with the logo of the issuing body on them. This means that both users and operating staff may not realise that a card issued by one operator is acceptable on the buses of other operators. Hence there is a need for standardisation of the cards and greater publicity about them so that everybody with a mental impairment who would find one useful, obtains one and knows how to use it, and that all transport operating staff understand the use of cards and respond appropriately when they are shown one.

Safe Place schemes, discussed in Section 5.5.5, are a very useful way of providing the reassurance that assistance can be obtained when required. However, the schemes do not exist everywhere and require organisation and management. There is scope for greater publicity about the existing schemes so that places which do not currently have them can understand the benefits of the schemes and how they can be organised. Similarly, tracking people with dementia who become lost using the Herbert Protocol, discussed in Section 5.5.6, offers a low cost way of providing reassurance to both the person with dementia and their carer so that, if the person does become lost, support systems can be put in place efficiently.

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<sup>313</sup> See note 2.

<sup>314</sup> See notes 1 and 3.

Providing people with mental impairments with clear information about how to make a journey can help their understanding of the various decisions that have to be made and how to obtain relevant information during the journey to inform such decisions. This can reduce some of the uncertainty associated with travel. However, the information has to be provided in a way that can be comprehended. Two ways of doing this are to produce inclusive travel guides and to provide information on websites and leaflets in ways that have been demonstrated to be useful to people with mental impairments. An obvious way to do this is to involve people with mental impairments in the design process. There are a number of examples of inclusive travel guides and good practice on how to communicate in clear English using appropriate fonts as discussed in Sections 5.4.1 and 5.4.2. There are no good reasons not to communicate travel information clearly, since this would benefit not only people with mental impairments but also the general public. For example, there seems to be no reason why printed bus timetables should appear in different formats across the country or that various Train Operating Companies (TOCs) should use different formats on the websites for presenting rail times and fares, or keep changing the formats. Consistency, following best practice, would ensure that, people with mental impairments who have learnt how to access travel information, are always able to do so, even when travelling in an unfamiliar area.

Special transport services such as dial-a-ride can be very useful for some people with mental impairments because they can take people door to door, removing the need to take decisions and talk to unfamiliar people. However, in many areas, people with mental impairments are not eligible to use such services or have to be accompanied by a carer, as discussed in Sections 4.5 and 5.3.3. The bodies providing the services, often local authorities, determine the eligibility to use the service.

There are ways in which the design of the local environment can be improved to make it easier for people with mental impairments to find their way around, for example, with clear, consistent signs, clear landmarks and a legible landscape without unnecessary clutter, so that, at decision points where there is a choice of route, it is clear what lies in each direction, as discussed in Sections 5.3.1 and 5.4.3.

Electronic information in the form of Audio-Visual Information (AVI) and mobile phone apps can be very useful for people with mental impairments because of their flexibility. AVI systems on buses and trains provide useful information to travellers, and reassurance that the person is on the correct route and the name of the next stop, as discussed in Section 5.4.4. Whilst this is useful for all travellers, it is particularly important for people with mental impairments who lack confidence. Whilst systems are in place in many areas, particularly in large cities, they are not universally available.

Mobile phone apps can provide information tailored to the needs of individual travellers when making walking journeys and travelling by bus or train, giving direction information and indicating, for example, when the correct bus has arrived or the stop for alighting at has been reached, as discussed in Section 5.4.5. There are a large number of such apps being developed

but not all are suitable for people with mental impairments. Whilst there is great potential in such apps, if they are to be useful it is important that people with mental impairments are involved in the design process and that the apps are evaluated by people with mental impairments to assess whether they are useful, and that feedback from the users is incorporated into the design.

Personalised travel planning, discussed in Section 5.7.1, offers great scope for meeting the travel needs of some people with mental impairments, particularly those who need to travel to common destinations such as day care centres or from common origins such as shared accommodation, by considering the trips they want to make at an individual level, taking into account their budgets, rather than assuming that the same method of travel is appropriate for everybody such as the local authority minibus. This may not only meet the needs of people with mental impairments better, it may save money. However, this needs some effective analysis and then creative thinking.

Dementia-friendly communities provide support when travelling and carrying out other activities outside the home for people with dementia, as discussed in Section 5.7.2. They are growing across the country. An area where the needs of people with dementia have been considered systematically, is likely to be one where people with other mental impairments can also travel around more easily. There is no reason why the whole country should not become dementia-friendly, and so more accessible for everybody with a mental impairment.

A second major factor, after anxiety and lack of confidence, deterring some people with mental impairments from using public transport is cost, as shown in Tables 11, 15, 16, 17, 23, and 24. Two ways of reducing the cost are concessionary travel passes for use on buses and Disabled Persons Railcards, as discussed in Section 5.6.2.

The English National Concessionary Travel Scheme (ENCTS) offers disabled people free off-peak bus travel, with equivalent schemes in Scotland, Wales and Northern Ireland. However, the interpretation of the criteria for eligibility for a pass varies across the country so that two people with the same condition living in different areas may be treated differently. Also some people with a mental impairment who are eligible for a pass may not be aware of it.

The Disabled Persons Railcard facilitates discounted travel for people with disabilities. Whilst the eligibility criteria are well defined, based on being in receipt of certain benefits, there is scope for allowing more disabled people to purchase a card, including some people with mental impairments. Given that some people with mental impairments have low incomes, that there are mental benefits of being able to travel more and that the traveller has to pay for their rail tickets, typically at a discount of one-third, there may be scope to consider the economics of Disabled Persons Railcards to explore whether there would be advantages to extending the scheme to more people with mental impairments.

Cars offer the opportunity to travel door to door without needing to interact with strangers which may suit some people with mental impairments, but many of them are not allowed to have a driving licence, so they can only travel as passengers. In Britain, the DVLA must be informed about many mental impairments, as shown in Table 26. Some people with conditions such as learning disabilities which are acquired about the time of birth, are never likely to be able to drive a car, but other conditions are acquired later in life, for example, dementia. In these cases, the person concerned may have driven for many years, but then suffer from loss of mental agility, judgement and memory, which means that they are no longer able to drive. However, because the condition is progressive, a critical issue is the point at which a person with dementia is no longer safe to drive. The evidence suggests that most people with dementia cease driving within three years of the first signs of the disease<sup>315</sup>. A difficult question is how the decision is taken, both in terms of how the person concerned is made aware that there may be an issue, and who decides<sup>316</sup>. In Britain a driving assessment can be carried out at a mobility centre, but this is relatively expensive and the number of centres is fairly small, so some people may live a long way from one. In the US there has been research into ways of using methods based on questionnaires and ratings by various people involved in the decision process<sup>317</sup>. Making such techniques available on-line may be useful as a first step in deciding whether a practical driving assessment is required and could be administered at home at little expense for the participant.

People with a condition that is acquired during the course of a lifetime, such as dementia, means that a person may be forced to cease driving. This has major implications for the lifestyle of the person concerned and their family who may be required to carry out many escort journeys<sup>318</sup>. Even with a supportive family, the reduction in independence and the opportunity for many social activities may be serious loss for many people who have to cease driving.

Some people with mental impairments are able to drive but need a subsidy in order to purchase a car in the same way as some people with physical disabilities, as discussed in Section 5.6.1. In some cases, this will enable them to be employed rather than remaining at home in need of benefits to provide their incomes. The eligibility criteria are defined in terms of the ability to walk a certain distance. However, some people with the mental impairments mentioned would benefit from more flexible rules which mean that mental factors influencing the ability to walk are included in the criteria.

Public car parks are often located some distance from shops and other destinations which can pose difficulties for people with certain mental impairments including dementia, autism and agoraphobia. Some people with dementia are elderly and cannot walk very far nor can they

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<sup>315</sup> See notes 153 and 161.

<sup>316</sup> See note 163.

<sup>317</sup> See notes 157 to 159.

<sup>318</sup> See notes 150 and 152.

be left on the street near the destination because they may wander off. Young people with autism may be behaving in a way that requires their carer to escort them to the car as quickly as possible, which may be difficult if the car is parked some way away. People with agoraphobia may not be able to cope with crowded or public places but are able to travel by car. Blue Badges for parking enable people with disabilities to park close to their destination, as discussed in Section 5.3.2. The eligibility criteria are the same as those for subsidised car purchase, that is, defined in terms of the ability to walk a certain distance. However, some people with the mental impairments mentioned would benefit from more flexible rules which mean that mental factors influencing the ability to walk are included in the criteria. This now happens in Wales.

Summing up, there is evidence that people with mental impairments are not travelling as much as they wish to. The main barrier to access for them is their lack of confidence and the need for reassurance when they travel. These can be provided through a variety of interventions. Whilst each intervention will assist some people, there is a need for some analysis of which intervention is effective for people with particular needs. It is quite likely that, if they could travel more easily, some people with mental impairments could contribute positively to the national economy rather than receiving benefits. A second set of barriers to travel relate to cost because many people with mental impairments have low incomes. However, if they could travel more easily various advantages may follow: not just positive contributions to the economy, but also savings from, for example, replacing traditional local authority minibus travel by more flexible approaches, and the mental health benefits of people getting out more and being part of the community. Many of the interventions discussed above are not very expensive. They just need setting up and managing.

The conclusions may be summed up as:

- A number of skills are used in travel, including recalling and assimilating information, taking decisions based on that information, having the confidence to travel alone, being able to communicate with other people and behaving in line with contemporary social norms;
- There are a number of mental impairments including dementia, autism, and mental health conditions that affect a person's ability to travel because they adversely affect these travel skills;
- People with mental impairments travel less than other people despite the evidence about the positive aspects of travel for people with mental impairments;
- The major reasons for relatively low levels of public transport use by people with mental impairments are anxiety and lack of confidence caused by a number of factors including the behaviour and attitudes of staff and other travellers, difficulty navigating along the street and through stations, the lack of accessible information at the appropriate time and concerns about becoming lost and possible disruption to the journey; other reasons include the cost of travel because many people with mental

impairments have low incomes and are not eligible for some travel facilities and concessions;

- Various interventions can be used to address these issues by:
  - Enhancing the travel skills of people with mental impairments;
  - Reducing the need for travel skills by simplifying travel and so reducing the need to make decisions;
  - Increasing the confidence of travellers by providing clear, accessible information at the appropriate time to assist decision making and reducing the risk of information being forgotten;
  - Improving the confidence of travellers by providing support from empathetic people during the journey;
  - Providing cheaper travel for people with mental impairments.
- The travel skills of people with mental impairments can be enhanced through travel training and providing experience using public transport;
- Journeys can be simplified by using coherent signage at critical decision points and simplification of the environment, by allowing use of special transport services such as dial-a-ride, and providing car parking near the destination for those who find it difficult to walk long distances, those who cannot be left alone or those who may need to be escorted away from other people quickly;
- Clear information in appropriate formats can be provided both before travel and during the journey; the former includes inclusive travel guides and coherent travel planning information, both on-line and on paper, the latter can be through clear signage, AVI and mobile phone apps;
- The confidence to approach staff can be increased by better staff training and providing travel assistance cards;
- There are a number of schemes that have been set up to increase the self-confidence of people with mental impairments to travel alone such as Safe Place schemes, tracking of people with dementia and schemes offering experiences such as using railways and bus stations, but they rely on local initiatives and not available across the country; these schemes are relatively inexpensive, so there is a strong case for sharing information about the schemes, for example, through a single website containing information about a range of initiatives that can improve accessibility for people with mental impairments;
- Mobile phone apps have great potential to assist people with mental impairments when travelling, for example by providing route information including directions at junctions when walking and real time information about bus arrivals, and by allowing monitoring of the person's location by a carer or agency; however, examination of the literature suggests that people with mental impairments are not always involved in the design and evaluation of such apps;
- People with some mental impairments are not eligible for some travel concessions such as concessionary passes for bus travel, Disabled Persons Railcards and reduced

price car leasing; changing the eligibility criteria could increase the mobility of some people with mental impairments;

- Some people with mental impairments are not aware that they may be eligible for some travel concessions, so publicity campaigns could be used to increase awareness;
- Personalised travel schemes based on the concept of analysing the travel needs of small groups of individuals in the context of the available budget offer the potential to meet the travel needs of people with mental impairments more effectively and save resources compared to more conventional approaches;
- Dementia-friendly communities offer people with dementia the opportunity to travel quite widely with confidence and have a well-defined path to implementation;
- People with degenerative conditions such as dementia have to give up driving, usually within three years of the diagnosis of the condition; because of the major implication of having to cease driving, how and when the decision is made can have a significant effect on their quality of life;
- There is evidence that the public have negative perceptions of people with mental impairments; these could be addressed through campaigns similar to those introduced to combat other forms of discrimination.

In conclusion, accessibility for people with mental impairments is relatively poor and there are many reasons why it should be improved. With a growing population of people with conditions such as dementia, there cannot be any excuse to ignore the issue, because it is not going to go away. Ironically, it would not be very expensive or difficult to make significant improvements: it just needs a clear vision and determination to address this very important issue. By doing so, society should benefit by becoming more tolerant and understanding, and people will know that, if they develop a mental impairment, life will be slightly easier than it is currently for people who live with these types of condition.