

### 1 CONTEXT

This Guidance Note has been produced by the CILT's Accessibility & Inclusion Forum following a seminar organised by the Forum in early 2017 on Understanding Mobility Issues for People with Hidden Disabilities.

The seminar was very well attended by local authority and transport operator representatives and demonstrated that understanding and meeting the needs of people with hidden disabilities is a key priority.

This Guidance Note draws on the key findings of the seminar and provides further sources of information on this important topic.

### 2 PURPOSE

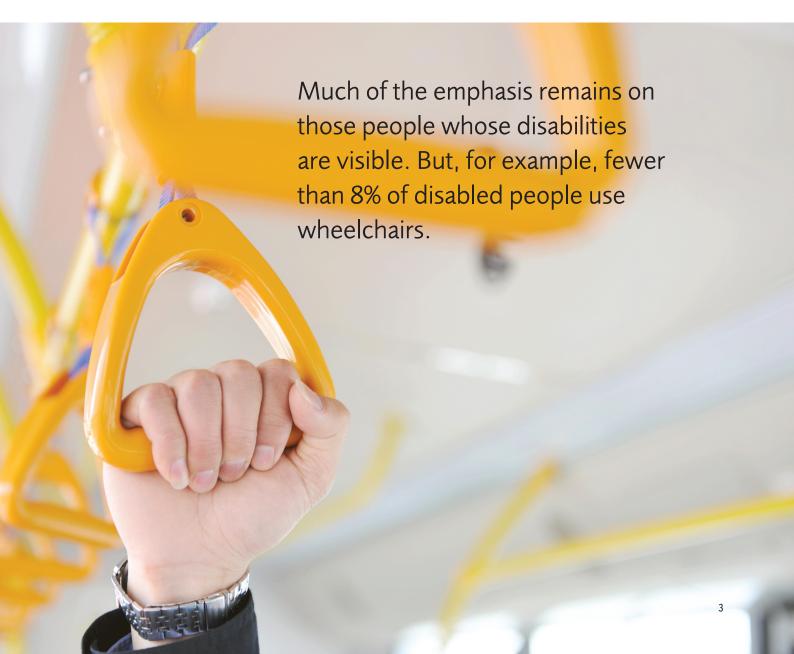
The purpose of this Guidance Note is to raise awareness among transport providers, local authorities, planners and designers of the needs of the very large number of people whose disabilities are hidden and so not visible to those around them.

For many, using public transport or the pedestrian environment is often severely challenging if not impossible.

### 3 INTRODUCTION

Staff working in the transport industries – as elsewhere – are now routinely trained in meeting the needs of disabled people. Similarly, transport infrastructure and the pedestrian environment is designed to meet legal standards for accessibility.

However, much of the emphasis remains on those people whose disabilities are visible. But, for example, fewer than 8% of disabled people use wheelchairs.



## **4 WHAT ARE WE TALKING ABOUT?**

It is difficult to give a clear or comprehensive definition of 'hidden disability'. Among the key issues are a wide range of mental health conditions. Mental health is the largest single segment of disability, affecting up to 25% of the population at some point in their lives and 10% of the population over the longer term.

A Government definition in the Life Opportunities Survey, includes dementia, autism, ADHD, dyslexia, anxiety and depression under the broad heading of mental health conditions.

In addition, there are many physical and sensory impairments that are also invisible to others. Many people with low vision or hearing loss, for example, may appear to have no difficulty in using public transport but may struggle with poor signage and inadequate oral or visual announcements.

People living with chronic pain may not look as though they need to be able to sit down on a bus or station platform, but without recognition and understanding from other passengers and staff, the journey may simply not be manageable. People with respiratory conditions may find walking even a short distance very taxing.

Many of those with hidden disabilities are older people who may be losing the confidence to travel for a variety of reasons including some loss of vision or hearing and difficulty with grip and balance. Older people may also be unsure that they have understood correctly what they are hearing or seeing. This leads to a sense of insecurity and a lack of self-belief.

### 5 WHY DOES IT MATTER?

It matters first because there is a legal obligation under the Equality Act 2010 and other legislation to remove barriers to access and free movement of anyone with a disability.

It also matters because there are very large and growing numbers of people whose ability to lead independent lives is reduced by an inability to travel. For example, dementia currently affects almost 1 million people in the UK and is forecast to increase by 40% over the next 12 years.

There is also a strong economic imperative to address these issues. Prolonging independent mobility is not only of huge benefit to individuals and their families, it is also of very significant benefit to the economy in terms of reducing levels of home and residential care and enabling some people with hidden disabilities to access employment.

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#### **6 WHAT CAN BE DONE?**

For the transport industries, there are clear indications of the reasons why people do not travel. For example, this table¹ based on data from the Government's Life Opportunities Survey (LOS) indicates the most important reasons why people with mental impairments do not travel by bus.

Table 1 indicates that anxiety and lack of confidence is the top reason, implying that people need to be given the confidence that they can make the journey and return home safely. For most people travel can be straightforward, but making decisions like whether to turn left or right at junctions can be challenging for people who cannot understand and process information from signs or remember where they are going.

A second message from the table is that overcrowding and the behaviour of other passengers can cause difficulties.

A third important issue is cost. Whilst cost can be an issue for all travellers,

many disabled people, including those with hidden disabilities, have low incomes because they cannot access highly-paid employment.

The first and most important message for improving accessibility is to recognise that it is not enough to put in a ramp and some colour contrasted hand rails and think that the job is done.

It is dangerous to generalise about the needs of people with hidden disabilities, those with mental health conditions will, for example, have very different concerns to those with low vision or chronic pain.

There will also be conflicting demands that operators and designers will need to balance. For example, while frequent audible announcements and good levels of lighting are vital to people with low vision or difficulty reading, people on the autism spectrum may find both of these features stressful and unpleasant. It is vital to listen to everyone's needs and then work on an acceptable compromise

rather than to react to the first or loudest voice in isolation. For example, while next stop or station information is vital to many, the entire list of menu choices from the buffet car on a train may not be and could be curtailed or withdrawn to avoid an overload of stressful noise.

There are, nonetheless, some clear common themes which can enhance the confidence of the traveller and improve the travel experience for everyone.

These include:

- Enhancing the skills of the traveller
- Simplifying the journey
- Providing clear information
- Providing support during the journey
- Making travel cheaper for people with hidden disabilities

#### Type of impairment

None	Learning	Intellectual	Behavioural	Memory	Mental Health
1. Transport unavailable	Cost	Anxiety/lack of confidence	Anxiety/lack of confidence	Anxiety/lack of confidence	Anxiety/lack of confidence
2. Cost	Transport unavailable	Cost	Cost	Difficulty getting on or off the bus	Cost
3. Other reasons	Anxiety/lack of confidence	Overcrowding	Overcrowding	Cost	Transport unavailable
4. Delay and disruption to service	Other reasons	Transport unavailable	Delay and disruption to service	Difficulty getting to stop	Difficulty getting on or off the bus
5. Too busy/not enough time	Delay and disruption to service	Attitudes of passengers	Fear of crime	Difficulty getting from stop to destination	Difficulty getting from stop to destination

#### Table 1

<sup>1.</sup> Mackett R L (2016) Improving accessibility for people with mental impairments, Paper presented at the European Transport Conference, Barcelona, October 2016, available from: www.abstracts.aetransport.org/paper/index/id/5003/confid/21

#### 6.1 ENHANCING THE SKILLS OF THE TRAVELLER

There are a number of useful initiatives run by local authorities, transport providers and others to enable people with a range of hidden disabilities to gain the confidence to travel.

Initiatives such as these not only enable more people to travel independently, it also reduces dependence on expensive dedicated door to door services such as dial-a-ride or ring and ride.

Familiarisation sessions are also very valuable, for example for people with dementia. In York the British Transport Police have taken the initiative to introduce rail familiarisation sessions for people with dementia to enable them to travel by train.

Air travel can be stressful for everyone even for the most experienced travellers - and for those with mental health conditions it can be enormously challenging.

Familiarisation can be very helpful and Virgin Atlantic invites those with anxiety about flying to visit the full scale cabin mock up at its base near Gatwick to discuss their needs and to see what the aircraft cabins are like.

#### Case Study: **Essex County Council Travel Training**

Essex County Council's Travel Training programme is designed to help people who need confidence to travel independently. This includes people who have behavioural difficulties, physical difficulties and additional needs to enable them to use public transport.

Being able to access public transport helps people to make their own choices about how they live and what they want to achieve.

Travel training can help overcome barriers to employment, social exclusion and independent journeys to school or college:

The scheme works through trainers who accompany trainees on their journeys, providing encouragement and guidance until they have developed the appropriate skills to travel independently.

The team of specialist travel trainers help to develop

- Coping with traffic on major roads, with and without pedestrian crossings
- · Learning the highway code
- · Confidence in using buses and trains
- How to plan a journey
- Familiarisation of travel routes and timetables
- Identification of landmarks
- Where to get help
- Personal safety
- Money skills.

The trainers can help prepare participants for travel on any specific journey - for example to work, school, further education or a training opportunity. Help is also available on walking routes.

#### Case Study: **British Transport Police, York**

British Transport Police are regularly approached by rail staff who need help when providing assistance to people living with dementia at train stations and when travelling across their rail network.

Recognising the pressing need for change, Fiona Andrews, a British Transport Police Officer in York began an initiative to improve things.

Fiona began by organising dementia awareness training for train station staff so that they could acquire greater understanding of the condition, and develop the skills needed to provide appropriate support to passengers living with dementia. Fiona also felt it was important for passengers living with dementia to have the confidence to use the rail network, and so arranged a number of short 'supported train journeys'. These provided an opportunity for people who had become nervous or reluctant to travel because of their condition to try rail travel again in a safe, supported way.

Fiona describes the project:

"My colleagues and I realised that people living with dementia sometimes found it difficult to travel by train or gave it up altogether. With the support of the Alzheimer's Society UK and Virgin East Coast Trains we organised some local, supported train journeys where we accompanied a group of 'reluctant travellers' on a short train journey to the seaside. We provided advice and support throughout the whole journey and even managed to stop off for a fish and chip lunch and ice creams. After taking part in a supported journey, and hearing about the passenger assistance schemes that are available across the rail network, many of the participants said they would be confident to travel again independently".

This initiative demonstrates how small changes can make a big difference.

## Virgin Atlantic explains its approach

Several years ago Virgin Atlantic Airways realised that many people with disabilities were avoiding flying as they had concerns about how they would cope within the plane. In addition, some customers who had not flown before were nervous about what the inside of a plane looks like - and whether the airline would be able to meet their individual needs and ensure an enjoyable flight. We decided to offer personalised, free of charge, visits to our training facility to anyone our Special Assistance team identified as needing extra support. The training facility contains 'rigs' which are mini versions of an aircraft cabin built to the dimensions of a dual aisle aircraft cabin and feature all classes of seats. Within a few minutes of entering a rig you feel as if you are in a real aircraft cabin. The rig visits enable an individual to gain confidence and explore - in a quiet environment - the inside of an aircraft, and become acquainted with the layout and noises they'd experience on a real flight.

Initially we concentrated on customers with physical disabilities as we thought they would have the most challenges with the inflight environment. However, a couple of years ago we received a request from a family with an autistic child who wanted to experience the rig. Their visit was a great success and we realised that our programme could benefit a much larger proportion of the disability community. We decided to widen out our offering to encompass customers with any type of disability who were really unsure if they could travel. We now find that the majority of our rig visits are for people with hidden disabilities such as autism, dementia and severe anxiety.

In our opinion it's a win/win offering for everyone concerned. The customer is more relaxed and has a better flight experience. The airline also attracts more customers as most people who thought they could not fly proceed to book a flight. We also learn something at every rig visit we host and we use this information to feed into our training programme, and continue to improve the experience we offer all of our customers. Enhancing our training helps our customer facing staff feel more confident and also provides better service to our customers.

If anyone is considering about flying on Virgin Atlantic and is unsure if this is possible please contact our Special Assistance team at special\_assistance@fly.virgin.com

### **6.2 SIMPLIFYING THE JOURNEY**

There are several ways in which the journey can be made simpler by removing the need to take some decisions.

One way to simplify walking journeys for people with cognitive impairments such as dementia is to make the local environment easier to interpret. 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. Signs should be simple with large dark text on a light background in clear colours. Long, uniform, repetitious streets and buildings frontages could be difficult, and so small well-defined spaces and short, direct routes without dead ends are likely to be less disabling.

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 UK '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. 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.

Unless they have a physical or visual impairment, people with hidden disabilities would need to make a case for a Blue Badge. This would involve demonstrating that they are unable to walk or 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.



A typical airport route from security to departures which can cause confusion and distress

## 6.3 PROVIDING CLEAR INFORMATION

For many people, lack of confidence stems from not being sure that they are on the right platform, train or bus. The presence of uniformed staff in a major factor in restoring confidence (and reducing fear of crime).

In addition, simple well placed information in both audible and visual formats is hugely important. Real time information at bus stops and on buses also enables people to travel confident that they won't face the embarrassment of having to ask for help to identify the right stop.

For people with autism, for example, smart phone journey planner apps can be very helpful. For those with a learning disability simplified journey information in the form of spider maps can be very useful.

Two examples below illustrate initiatives in the West Midlands.

Clear information is also essential in the pedestrian environment and in transport buildings such as stations and airports.

Too much signage can be as bad as too little and often serves only to confuse. Clear lines of sight, information at eye level and in large clear fonts with good colour contrast make a significant difference to people's ability to manage independently.

For some people, for example, those with autism, noise, smell and overcrowding are all major stress points. The current design trend in airports to lead all passenger through the duty free shopping area between security and their departure gate is particularly difficult for many people including those with mental health conditions, low vision or simply difficulty in walking extended distances without pain.

#### Transport for West Midlands Spider Map



## Transport for West Midlands Journey Planner - web and app



### 6.4 PROVIDING SUPPORT DURING THE JOURNEY

In addition to the simple presence of staff as a key source of information and reassurance, ensuring that staff have had the right training to be able to recognise and support people with hidden disabilities is also vital.

Disability awareness training is a legal requirement in the transport industries as elsewhere but in many cases it focusses on the needs of wheelchair users and others with disabilities that are easy to identify. Training in these area in recent years has enormously improved the travel experience and confidence of many people with disabilities and must continue to be delivered and developed.

However, there also needs to be training in the much broader and less well defined area of hidden disabilities so that staff in direct contact with the travelling public do not make assumptions that can cause anxiety and distress.

There are some excellent examples of training already in progress. In the West Midlands, for example, autism awareness training is delivered to the West Midlands Combined Authority and Transport for the West Midlands customer facing employees and autism champions have been introduced in bus stations and travel shops.

WMCA also funds the delivery of mental health awareness training to the major bus operator in the region (National Express) and this training has now been mainstreamed as part of their day to day training.

TfWM also publish an annual Getting Around Access Guide<sup>2</sup> which includes examples of their key accessibility products to help ease people's travel.

In Liverpool, the Dementia Action Alliance is working across the transport sectors to raise awareness and deliver appropriate training. Recent initiatives include:

- A staff awareness session in an Arriva bus depot
- A meeting with Liverpool Airport staff to discuss particular needs of people with dementia
- Pilot training with Virgin West Coast Trains staff
- Working with Merseytravel to include dementia awareness in induction training for staff

Other initiatives that can be very useful, on a voluntary basis, include assistance cards that those whose disability is not apparent can use to show to a bus driver or other staff member that they have a particular disability or special requirements such as having their change counted. This can avoid the often embarrassing exchanges that can take place between driver and passenger challenging someone's entitlement to concessionary travel, for example.

For those who need a seat near the door, perhaps because of chronic pain, such a card can also be helpful in informing other passengers discretely of their need.

There are also trials, such as at Gatwick airport, with use of a distinctive lanyard which indicates to staff in security and other places that the wearer may need additional assistance.

Not everyone with a hidden disability welcomes or wants this form of identification, but it can be a useful tool for those who would like to use it.

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 he or she comes to meet them, if that is their desired course of action.

An example is the Bradford Safe Place Scheme 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.

#### Case Study: **The Herbert Protocol**

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 issued by West Yorkshire Police, 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 and distress if it enables a lost person to be found quickly.

<sup>2.</sup> https://static.centro.org.uk/documents/nwm/gag/GAG-2016.pdf

Many people with hidden disabilities are not aware that they are eligible to have a concessionary bus pass

### 6.5 MAKING TRAVEL CHEAPER

Many people with hidden disabilities are wholly reliant on public transport for their travel but they may also be low earners or unable to work because of their condition.

There is currently no consistent policy across local authority areas on the interpretation of the eligibility of people with mental health conditions, for example, for a concessionary bus pass. In some cases, those who have to travel across county or national boundaries (for example between England and Wales) may find that they are entitled to a concessionary pass on one leg of the journey and not on others. While this lack of consistency can also apply to others, the uncertainty and potential confusion can be particularly distressing to those, for example, with mental health issues or a learning disability.

Providing an affordable means of travel for those with hidden disabilities is just as important as it is for those who travel with a wheelchair or a guide dog. Many people with hidden disabilities are not aware that they are eligible to have a concessionary bus pass, while those that do have them often find the rules about when and where they can be used confusing. Also, local authorities do not always interpret the guidelines about eligibility in the same way, so two people with the same condition but living in different areas, may be assessed differently.



## **7 CONCLUSIONS**

As this Guidance Note has set out, the key to meeting the needs of people with hidden disabilities is giving confidence. That can be done in many ways and take many forms depending on the mode and type of operation and the particular needs of the individual traveller.

Common themes across all modes and circumstances include:

- Simple, accessible and unambiguous wayfinding, signage and information (both spoken and written);
- Straightforward and consistent policies on issues such as concessionary fares;
- Human support both to help those who need it to have the confidence to travel in the first place, and throughout the journey to give confidence and reassurance.







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