Cognitive Impairment, Mental Health and Transport

Design with Everyone in Mind

OECD

International Transport Forum

INTERNATIONAL TRANSPORT FORUM

The International Transport Forum is an inter-governmental body within the OECD family. The Forum is a global platform for transport policy makers and stakeholders. Its objective is to serve political leaders and a larger public in developing a better understanding of the role of transport in economic growth and the role of transport policy in addressing the social and environmental dimensions of sustainable development. The Forum organises a Conference for Ministers and leading figures from civil society each May in Leipzig, Germany.

The International Transport Forum was created under a Declaration issued by the Council of Ministers of the ECMT (European Conference of Ministers of Transport) at its Ministerial Session in May 2006 under the legal authority of the Protocol of the ECMT, signed in Brussels on 17 October 1953, and legal instruments of the OECD. The Forum's Secretariat is located in Paris.

The Members of the Forum are: Albania, Armenia, Australia, Austria, Azerbaijan, Belarus, Belgium, Bosnia-Herzegovina, Bulgaria, Canada, Croatia, the Czech Republic, Denmark, Estonia, Finland, France, FYROM, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Italy, Japan, Korea, Latvia, Liechtenstein, Lithuania, Luxembourg, Malta, Mexico, Moldova, Montenegro, Netherlands, New Zealand, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey, Ukraine, the United Kingdom and the United States.

The OECD and the International Transport Forum established a Joint Transport Research Centre in 2004. The Centre conducts co-operative research programmes addressing all modes of transport to support policy making in Member countries and contribute to the Ministerial sessions of the International Transport Forum.

Also available in French under the title:
Déficience cognitive, santé mentale et transports : Vers une accessibilité pour tous

Further information about the International Transport Forum is available on Internet at:
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FOREWORD . . . .

Cognitive impairment affects a large and growing number of people and encompasses a wide range of conditions from autism to age-related dementia and stroke. Mental health problems also impact large numbers of people, with one in four individuals affected at some point in their lives.

For people both with cognitive impairment and those with mental health problems, using public transport can be a traumatic and challenging experience, and for many, simply impossible.

While much is being done to improve vehicles and infrastructure to meet the needs of people with physical or sensory impairments, the issues of cognitive impairment and mental health are largely neglected. There is a significant untapped transport market for people who currently lack the confidence or understanding to make journeys.

A limited amount of research has been conducted in recent years to enhance understanding of these issues and to suggest ways of overcoming the transport problems that people with cognitive impairment and mental health problems face.

Many of the solutions are simple and low-cost, and by following the principles of universal design, can also produce benefits for the wider travelling public.

The practical steps that can improve people's ability to use public transport include training of transport staff and familiarisation of people with cognitive impairment or mental health problems with the transport system to help build or restore their confidence.

Information is also key, and traditional ways of presenting timetable and other transport information need to be re-considered. Other key factors include the use of both audible and visual information and simple and clear signage. Physical design features and the presence of staff can also help to build confidence.

This report is intended to help those who plan, design and run transport systems and transport infrastructure to understand the issues that affect this significant proportion of the population and, in so doing, to find practical ways to improve their services and facilities for the travelling public as a whole.

INTRODUCTION ....

Transport accessibility: context and progress

It is now widely recognised that accessibility is an important factor in ensuring a high quality, efficient, sustainable transport system. It is no longer generally regarded as an issue of concern only to a minority of people - in particular disabled people whose travel needs are seen as different from those of the general population.

The demographic changes which affect all of us indicate very clearly that the number of older people in the population will increase significantly. For example, in Europe, the proportion of the population over 65 will increase by 40% in the next 30 years and the share of all people over 80 will double. It is also well understood that there is a strong correlation between age and disability: two thirds of disabled people are older, and over half the population aged over 75 has some form of disability[1].

Older people are the fastest-growing segment of the population in most developed countries.

The growing imbalance between working age people and older people will have profound social and economic implications. There will not be enough younger people to support an older population that is not self-sufficient. Personal mobility and access to public transport are essential components of independent living.

These trends must also be seen alongside the already significant population who have mobility problems. Between 20% and 30% of people travelling have a mobility difficulty at any given time. In the countries of the European Union currently upwards of 45 million people (roughly one in six) have a disability.

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1. *www.internationaltransportforum.org/europe/ecmt/accessibility/pdf/CM200607Fe.pdf*

The European Conference of Ministers of Transport (ECMT), now the International Transport Forum, has been active for over 20 years in improving understanding of the transport needs of disabled and older people at political level and in putting forward practical solutions to them, in both policy and technical terms.(See website *www.internationaltransportforum.org/europe/ Archives.html*).

Transport Ministers have endorsed and supported these initiatives and have recognised that[2]:

- *All policy initiatives or developments in transport and land use planning should include an evaluation of their potential impact on safety and accessibility of older and disabled people.*

- *All links in the transport chain need to be improved so that an accessible environment is created door to door, and increased efforts must be made to connect the different means of transport and thereby create an integrated, safe and accessible transport system.*

- *In particular, all new investments in transport must take account of and plan for the needs of older and disabled people in accordance with the Charter adopted by Ministers in Warsaw in 1999[3].*

- *Close co-operation between governments, public authorities, manufacturers, operators and the people concerned is essential.*

Many countries have taken strong initiatives based on these principles and have introduced legislation, regulation or other forms of support or incentive to ensure that accessibility is integral to transport policy and development.

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2. *www.internationaltransportforum.org/europe/acquis/dis20013e.pdf*

3. *www.internationaltransportforum.org/europe/acquis/tphCharter.pdf*

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Cognitive impairment and mental health:
A gap in transport policy and service provision

There are, however, two groups of people whose mobility needs are little understood by both governments and transport service providers: people with cognitive impairment and those with mental health problems.

The ECMT has highlighted this gap in accessible transport policy. A paper outlining key policy messages on improving transport accessibility for all, presented at the Council of Ministers in Dublin in 2006[4], noted that:

"these disabilities continue to be under-represented in accessible transport policy. Disability comes in many forms: it is not enough to pay attention only to the needs of those in wheelchairs or with walking difficulty. People with a loss of vision or hearing (both very commonly associated with the ageing process) and those with intellectual disabilities or mental health problems also have particular needs that can be addressed without significant cost."

A joint initiative between the ECMT and the UITP (The International Association of Public Transport) on improving access to public transport has included the publication of Guidelines for Transport Personnel[5]. These guidelines specifically address the need for transport staff to be trained in recognising and understanding the needs of people with cognitive impairment and mental health problems.

Objectives of this report

The purpose of this report is to highlight the difficulties that public transport can create for people with mental health problems or with cognitive impairments; examine how these difficulties affect people's ability to use public transport and

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4. *www.internationaltransportforum.org/europe/ecmt/accessibility/pdf/CM200607Fe.pdf*

5. "Improving Access to Public Transport: Guidelines for Transport Personnel." (75 2006 09 1 P), May 2006, 27 pages + CD-ROM, ISBN 92-821-0357-9.

travel independently; and suggest what can be done to address the difficulties both in practical and policy terms.

Accessibility for people with cognitive impairment or mental health problems, as for people with other kinds of disability, is not only a social issue. There are also strong economic arguments for enabling people to attain, retain or regain independent mobility. The cost to society of providing support for people who are unable to live independently is very high.

There is also a significant – largely off-peak – market for the transport industries in providing for the needs of people who are predominantly non-drivers and for whom public transport is the only option.

There has been relatively little quantitative research in this field but there is some significant qualitative research involving studies of groups of people with a range of cognitive impairments and mental health problems. This report draws heavily on the work carried out for the ECMT by Professors Agneta Ståhl and Susanne Iwarsson of Lund University in Sweden[6]. Their work has, in turn, drawn on the European Commission-funded MAPLE project[7] and on Swedish research at Lund University[8].

The recommendations in this report also include the input of organisations and individuals who live with these issues or represent those who do[9].

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6. Persons with Cognitive Impairments and Public Transport CEMT/CS/AI(2005)5/REV2.

7. Improving Mobility and Accessibility for People with Learning Disabilities in Europe (MAPLE).

8. "Accessibility in Public Transport for Persons with Cognitive Impairments – Survey, Methodological Development and Innovative IT solutions." (REKO)

9. Mental Health Europe, Inclusion Europe, MENCAP (UK), Centre Rencontres pour personnes traumatisées cérébrales, Switzerland.

HOW MANY PEOPLE? WHO ARE THEY? . . . .

Taken together, cognitive impairment and mental health problems affect a large number of people across countries.

This report will refer to cognitive impairment and mental health problems largely in functional rather than medical terms. The issue here is to discuss what aspects of public transport people find difficult or impossible and how the barriers and problems which our public transport systems currently impose can be tackled and alleviated.

Although there are very different issues affecting people with cognitive impairment and mental health problems, there are also some common difficulties. Individuals with cognitive impairment may also have mental health problems and people with mental health problems may, similarly, have some degree of cognitive impairment. In functional terms and in a transport context many of the problems that arise and the solutions to them are common to both – and indeed will often benefit a much wider population too.

Cognitive impairment

The term "cognitive impairment" encompasses a wide range of conditions from learning disability, autism or traumatic brain injury to age-related dementia or stroke. In functional terms it can be taken to mean anyone whose ability to "perceive, organize and integrate information has been affected by their condition"[10].

The term "learning disability" refers to a lifelong condition, usually present from birth or that develops before the age of 18. It is a permanent condition, and people with learning disabilities may have impaired skills in areas such as cognition, language, motor and social abilities.

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10. Abreu BC & Toglia JP(1987) "Cognitive rehabilitation: a model for occupational therapy".

However, they also have a wide range of abilities. Some people can live independent lives and will need help only in some very specific areas (for example some people can read but have difficulties with numbers; some people can count and calculate but have difficulties telling the time, etc).

Because of the close link between cognitive impairment and predominantly age-related conditions such as stroke and dementia, the number of people in the population with these impairments is increasing with the growing proportion of older people.

Dementia and related neurological conditions affect 10% of people aged 65 plus. In people aged over 85, around 50% have some form of cognitive impairment ranging from mild to severe dementia.

Stroke is one of the most common causes of cognitive impairment. To take just two examples, in Sweden 25 000 to 30 000 people every year have a stroke while in Britain the annual figure is 150 000. Increasingly people are surviving strokes (there are almost 1 million people in Britain today who have had strokes) but many are left with residual physical and cognitive impairments. Common side effects of stroke include tiredness and loss of concentration. Many people give up or greatly reduce their use of public transport following a stroke and many also give up driving.

Cognitive impairment is not, however, solely age-related. Many children and younger people will also be affected. For example, traumatic brain injury is another common cause of cognitive impairment. Incidence of traumatic brain injury is in the order of 235 per 100 000 across Europe with road traffic accidents representing a major cause.

Mental health problems

While cognitive impairment will predominantly affect a person's concentration, memory and communication, people with mental health problems are likely to have difficulty with their emotions, behaviour and generally with coping in a challenging environment.

One in four individuals will experience mental health problems at some point in their lives[11].

A great deal of stigma and prejudice is still attached to mental illness, and there is much emphasis now on enabling people with mental health problems to reintegrate into society rather than being shut away from it. Independent mobility is not only a vital part of the rehabilitation process, helping people to rebuild confidence in social interaction, it is also an essential means for people to reach treatment and support networks.

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11. World Health Organisation, *www.euro.who.int/mentalhealth*

WHAT ARE THE TRANSPORT ISSUES? . . . .

The problems experienced by people with cognitive impairment or with mental health problems are not physical, although many people with cognitive impairment (for example those who have had strokes) may also have some mobility difficulties.

Source: © Iconotec.

The main problem can be characterised as difficulty in coping with a fast-moving and constantly-changing environment. Using public transport involves processing information quickly and taking decisions based on that information.

In practical terms people with cognitive impairment can also have difficulties communicating with other people, or with finding their way around. This is because their capacity to concentrate, reason and remember may be affected.

Mental health problems may also cause social skills limitations which, combined, may reduce functional capacity and the ability to perform everyday tasks associated with travelling.

Particular problems in the day-to-day transport environment for both groups of people can include:

- *Getting one's bearings.*

- *Tiring easily.*

- *Being unable to concentrate or remain vigilant.*

- *Being anxious.*

- *Becoming stressed as a result of hurrying/coping with deadlines.*

- *Struggling to cope with information in small print, poor acoustics, fast speech etc.*

- *Remembering information.*

- *Dealing with unexpected or stressful situations.*

- *Lack of information during the journey.*

- *Fear of falling.*

- *Lack of understanding/empathy from transport staff (cognitive impairment and mental health problems may not be visible).*

- *Stigma, discrimination, abuse.*

Most of these are problems that we have all experienced to some degree at one time or another while travelling, for example, in an unfamiliar environment, in a country with whose language or customs we are not familiar, when we are tired or when the expected route or timetable is disrupted for any reason.

The impact on someone with a cognitive impairment or with a mental health problem will, however, be much greater and may deter them from attempting to use public transport again.

WHAT CAN BE DONE? . . . .

Universal design

The key, as is often the case, lies in solutions that will enable everyone to travel with less stress and greater confidence. The concept of universal design is very important here. Following the principles set out below and, above all, focussing on making transport "simple and intuitive" to use will result in transport systems that people can use more easily.

The table below sets out the seven principles of universal design[12].

	Principle	Definition
1	Equitable use	Useable and marketable to people with diverse abilities
2	Flexibility in use	Accommodates a wide range of individual preferences and abilities
3	Simple and intuitive use	Easy to understand, regardless of experience, knowledge, language skills or current concentration level
4	Perceptible information	Communicates necessary information effectively regardless of ambient conditions or sensory abilities
5	Tolerance for error	Minimises hazards and adverse consequences of accidental or unintended actions
6	Low physical effort	Can be used efficiently and comfortably with a minimum of fatigue
7	Size and space for approach and use	Appropriate size and space for approach, reach, manipulation, and use regardless of body size, posture or mobility

12. Center for Universal Design, North Carolina State University, NC, US (Folette Story 2001).

Education

There is very little awareness of the issues facing people with cognitive impairment or mental health problems among those responsible for the planning and delivery of public transport services and infrastructure.

A survey undertaken as part of a recent European Commission-funded project[13] revealed a high level of ignorance or misunderstanding about the nature of these conditions and their implications for the way in which public transport is run.

Some basic information and tuition on these issues as an integral part of professional training and qualification in all transport-related disciplines would be helpful alongside the growing body of material that is available on physical and sensory impairments.

Practical steps

In parallel, some of the simple, often low-cost initiatives that can be very helpful include:

Before the journey

Travel awareness training

This is a technique to help an individual with a learning disability, for example, build up the confidence necessary to make a routine journey unaccompanied, perhaps a daily trip to school or college.

It involves making the journey accompanied by a trainer, who will find the most easily manageable options for the journey and explain each step as the journey progresses, including strategies for coping if the unexpected happens – for example the bus does not arrive or the route is changed. This can be a very successful way to help someone with a cognitive impairment or mental health problem to break their dependence on door-to-door transport or to attempt to travel for the first time.

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13. Improving Mobility and Accessibility for People with Learning Disabilities in Europe (MAPLE).

Here to there
with Merseytravel

An education pack promoting access to public transport
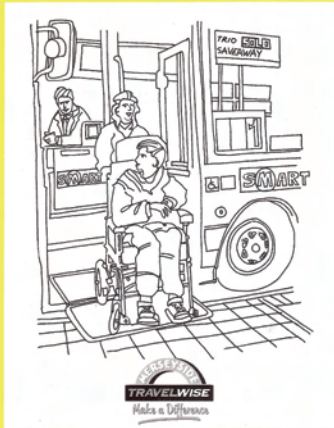
In a number of areas, "buddies" or travel companions are provided by the operators of the local transport or door-to-door service provider. There are also examples of schemes that provide a structured programme of support with the aim of enabling the individual to gain both the skills and the confidence necessary to make the journey alone. Schemes of this kind have been carried out in France, Ireland, the Czech Republic and in England.

In some areas, travel training/support schemes are backed up by information material produced specifically for people with cognitive impairments. Merseytravel in the UK has produced "*Here to There with Merseytravel*" which includes illustrated fact sheets showing how to make a journey by bus, train or ferry.

Similar initiatives aimed specifically at children can also be successful. A scheme in Athens is run by a training centre which fosters the social and vocational integration of young people aged 14 to 21 with cognitive impairments. This involves practice-based learning, which leads to the development of a "cognitive" map for each individual student to understand and cope with their journey.

The use of games to help younger children with cognitive impairments is also valuable. In Sweden, help is available on the internet for parents of children with cognitive impairments who want to teach their children to travel safely and independently.

A similar approach, using a game as part of an "Independent Travel Package", has been produced by the local authority in Warrington in the UK.

University College London has also produced "Going Places" (illustrated), an interactive travel training game aimed at young people with cognitive impairments[14]. The game uses photographs of landmarks and places of interest along a chosen bus route. It has been found to be very helpful in assisting students to memorise bus routes and so enable them to travel with greater independence.

Pre-journey information

Travel information produced by transport operators often pre-supposes that people are familiar with using public transport and therefore does not provide sufficient basic information for those who may never have done so – whether because of physical, sensory or cognitive impairment.

Attention to the way in which information about using a route or system is both produced and disseminated can also benefit the growing number of older people who have had to give up driving and may seldom have used public transport.

During the journey

Training of front line transport staff

Training can be a valuable tool in helping staff to recognise and assist people with cognitive impairment or mental health problems. This does not mean expecting staff to be experts in diagnosis, simply to show empathy.

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14. www.cts.ucl.ac.uk/arg/Research/Projects/Trumpet/index.asp

One of the key persistent problems is discrimination born out of ignorance. There is still too often perceived stigma attached to cognitive impairment and mental health problems, and there are many examples of insensitive and even cruel treatment by drivers, station staff and fellow passengers.

Effective training is generally best delivered by people with personal experience of living with cognitive impairment or a mental health problem.

Audible and visual information in parallel

It is already a legal requirement under disability discrimination laws in some countries to provide all information in both audible and visual forms, but the norm in many places is still to give either visual information (for example regarding train departures) or audible information (for example, announcing from which platform a train will depart).

Providing all information as a matter of routine in both audible and visual form provides additional assurance to the whole of the travelling public. It is vital to those people whose sight or hearing is impaired and provides essential reassurance to people with cognitive impairment or mental health problems.

Simple, clear information and signage

Too much information can be as distracting and confusing as too little. Information (both audible and visual) should be restricted to what is essential to enable people to find the right platform/departure gate/vehicle, and to be aware of any changes to that information. Again, this can benefit the travelling public as a whole.

Many people struggle to understand maps when they travel by public transport, and the simplified "spider maps" of London's bus and underground network, developed with the help of people with cognitive impairments, have proved to be very popular with the travelling public as a whole. (See illustration)
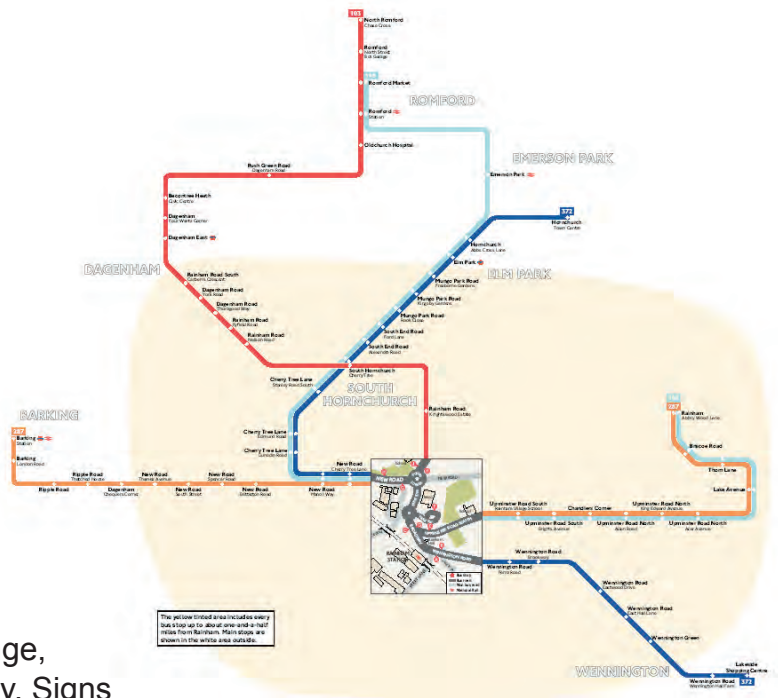
Similarly, too many signs in, for example, a rail or bus interchange, will add to confusion and anxiety. Signs need to be kept to a minimum in order to be clear and unambiguous.

Pictograms or icons can be helpful, provided that they are immediately recognisable. The city of Pisa, Italy has made use of coloured icons to aid route guidance (shown at left).These can be particularly helpful to people who cannot read or who do not know the language of the country. However, it is essential that the range of colours used, for example to distinguish between lines in a system, should be kept to the minimum necessary for clarity.

Umedalen

Vasaplan

The local transit authority in Umeå, Sweden, uses pictograms specifically intended to help people with cognitive impairments. Signs on the side of the bus provide a simple illustration of a well-known landmark associated with a particular destination.

Another example of an intuitive and uncomplicated sign which has proved successful comes from Liverpool, where a large footprint with the word "Bus" written inside it has been painted on the pavement to indicate the direction to the bus stop.
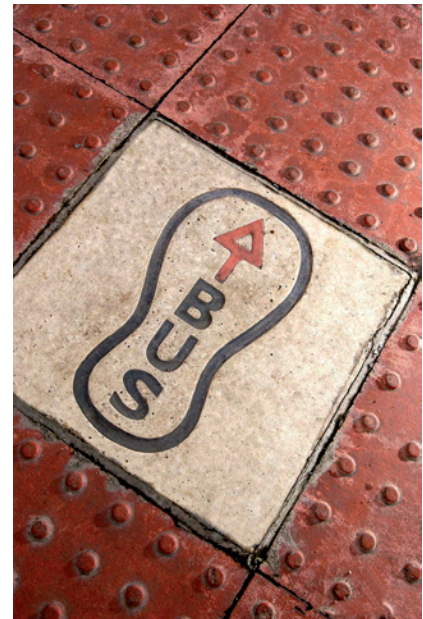
Presence of staff on vehicles and at interchanges

The presence of staff on vehicles and at interchanges is reassuring to all travellers both in terms of information and assistance and personal security. This does not necessarily mean having staff available on all vehicles at all times (although this is greatly valued by passengers). The LUAS system in Dublin, for example, includes a button on all ticket machines which can be pushed to activate audio assistance and, if need be, personal assistance.

Travelling companions can also be important for those people who would not otherwise be able to make a journey alone - even with training. In Paris, transport providers combine to offer a service known as "les compagnons du voyage". This scheme provides a trained escort for anyone who feels the need to be accompanied on public transport. The pool of escorts includes people trained to meet specific needs, for example using sign language or guiding a blind person.

Real-time audio/visual information at stops

In a growing number of cities, real-time information is now available at bus stops indicating how many minutes before the arrival of the next bus and which buses use that stop. Again, this can be particularly reassuring for anyone with a cognitive impairment, but is also greatly valued by anyone anxious about how long they may have to wait, or unsure if they are at the right stop.

Physical design features

The design and layout of transport interchanges can have a significant impact on the confidence that people feel in using that facility. One key feature is clear sight lines at rail or bus stations so that passengers can see immediately where different facilities are located and how to reach them.

A good example is in Malmö, Sweden, where the station facilities have been reorganised in a much more coordinated and uncomplicated way. For example, the new layout draws travellers' attention to the station clock more easily. This kind of universal good design is helpful in addressing concerns about personal security as well as for information and orientation.

Malmö station - Before

Malmö station - After

Tactile surfaces, intended primarily to guide people who are blind or partially sighted, can also give helpful visual or physical directional cues to people with cognitive impairments.

Such systems in use in Athens and Washington, DC., for example, use flashing lights built into the platform to indicate that a train is entering the station, and thereby help to alert people with a cognitive impairment as well as those with impaired sight or hearing.
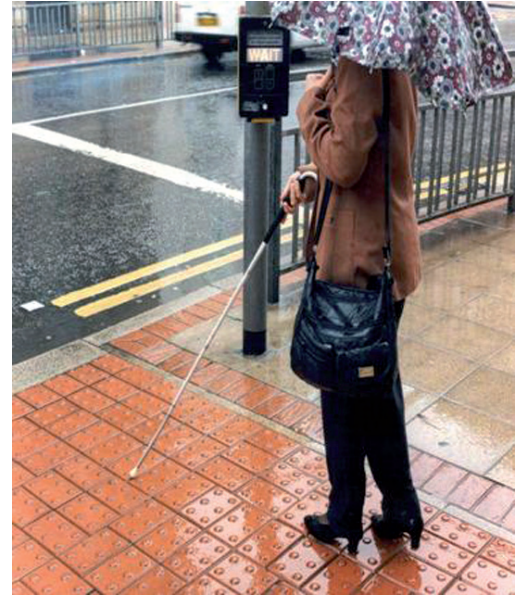
Technology

Several types of technical aids can be useful as well. For example, a Swedish company has developed a "quarter-hour clock", which shows the number of quarter-hours remaining before a predetermined activity. A "palmtop" computer with tailored programmes for people who have problems finding their way has also been developed.

In Warrington, UK, the "Independent Travel Pack" produced by the local authority includes a key fob to activate real-time audio information at stops.

CONCLUSIONS AND RECOMMENDATIONS . . . .

It is clear that the transport challenges faced by people with cognitive impairment or mental health problems are not yet well recognised or understood either at political or executive levels in the transport field. It is also clear that, although there are examples of good practice around Europe, they are by no means universal, nor are they routinely or systematically evaluated to measure their effectiveness.

This is an area in which major information gaps persist, and efforts should be made in government to commission the necessary research to fill those gaps.

There is, however, a great deal that can already be done. This report has set out to illustrate that it is possible for transport providers and planners to make a significant difference to the lives of a large and growing number of people simply by the application of principles of universal design and by addressing the functional needs of public transport users as a whole rather than the specific and therefore "special" or "minority" needs of particular disability or impairment groups.

The diagnosis or medical history of an individual is irrelevant in transport terms. What is important is not whether a person has Alzheimer's disease or schizophrenia, but that they share a common difficulty with perception and memory. That difficulty – and many others highlighted in this report – is also shared to a greater or lesser extent by the vast majority of the travelling public at some time and in some conditions.

To reiterate, the steps that can be taken to alleviate the difficulties specific to people with cognitive impairment and mental health problems are generally simple, low-cost and will benefit the travelling public as a whole.

In summary, they include:

Before the journey

- Travel awareness training to help people build confidence and develop coping strategies.

- Timetable and other pre-journey information which recognises that people are not familiar with public transport and provides clear basic information.

During the journey

- Training front-line staff to recognise, assist people and to show empathy.

- Providing journey information in both audible and visual formats.

- Keeping information and signage simple, clear.

- Having staff available on vehicles and at interchanges.

- Real-time information at stops in audio and visual formats.

- Station/interchange design and layout that is simple and uncluttered.

- Technical aids, for example to help those who cannot remember a route.

Underlying the practical recommendations and good practice examples given in this report is the clear principle that empathy and understanding of people and their needs are at the heart of good transport planning and delivery.

Whether people have a cognitive impairment, a mental health problem or are simply tired and distracted after a busy day, the same design features and principles of service delivery will benefit them and encourage them to continue to be public transport users.

For more information on cognitive impairment and mental health problems

INCLUSION EUROPE IASBL

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Inclusion Europe is a non-profit organisation that campaigns for the rights and interests of people with intellectual disabilities and their families throughout Europe, promoting **Respect, Solidarity** and **Inclusion** and against discrimination. Inclusion Europe co-ordinates activities in many European countries, including conferences, working groups and exchange meetings. It responds to European policy proposals and advises the European Commission and members of the European Parliament on disability issues.

For further information about Inclusion Europe IASBL, please visit: *www.inclusion-europe. org* **or contact:** *secretariat@inclusion-europe.org***, tel. : +32-2-502 28 15, fax : +32-2-502 80 10**

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Mental Health Europe is a European level non-governmental organisation (NGO) and network committed to the promotion of positive mental health and well-being, the prevention of mental disorders, the improvement of care, advocacy for social inclusion and the protection of the human rights of people with mental health problems and their families and carers. MHE represents the common interest of its members and lobbies and advocates for it at the European level.

For further information about Mental Health Europe, please visit:
*www.mhe-sme.org***, or contact:** *info@mhe-sme.org***, tel: +32 2 280 04 68, fax: +32 2 280 16 04.**

Both are member organisations of the European Disability Forum.