

COGNITIVE IMPAIRMENTS, MENTAL HEALTH AND TRAVEL

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1. INTRODUCTION

The purpose of this paper is to examine the barriers to travel for people with mental health conditions and cognitive impairments. Equality legislation and the nature of the conditions are discussed briefly in the next section. Then the difficulties encountered by people with the conditions when travelling are presented. The paper is concluded with discussion about some of the interventions that can be used to help overcome these difficulties. Most of the discussion is about using public transport because that is the mode available to most people with the conditions.

2. COGNITIVE IMPAIRMENTS AND MENTAL HEALTH CONDITIONS

The Equality Act 2010 prohibits discrimination against people with certain characteristics including having a disability. Under the Act "a person has a disability if they have a physical or mental impairment which has a substantial and a long-term adverse effect on their ability to carry out normal day-to-day activities" (Department for Work and Pensions, 2013).

There is a distinction between an impairment and a disability. According to the Department for Work and Pensions (2013):

- 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 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 with the Equality Act 2010.

'Day-to-day activities' include travelling, both as an activity in its own right and as the means of accessing various employment, educational and leisure

activities which is necessary to participate in them fully. This means that barriers to travel for those with physical or mental impairments need to be overcome to enable them to contribute to and enjoy the benefits of society.

Much work has been done to reduce the barriers to travel (Department for Transport, 2005), but much of the emphasis has been on investment in engineering solutions to overcome environmental barriers. For example, ramps have been constructed to enable people in wheelchairs to change level and access buildings and tactile paving has been installed to assist blind people in wayfinding on the street. However, it can 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.

A mental impairment, the term used in the Equality Act 2010, could arise from a mental health condition or from a cognitive impairment. Mental health conditions include anxiety, phobias including agoraphobia, depression, bipolar disorder, panic disorders, anger management issues, post traumatic stress disorder and personality disorders such as schizophrenia. According to Mind and Rethink Mental Illness (2008) 1 in 4 people experience a mental health problem in any given year. Many of the conditions are treatable, and so do not affect people for their whole lives. People with mental health problems may have difficulty with their emotions, behaviour and generally with coping in a challenging environment (International Transport Forum, 2009) so travelling may be difficult, especially when decisions are required, for example when a train or bus is cancelled or when it is very crowded. Not everyone who has a mental health condition is disabled nor do they necessarily have difficulty making a journey.

The term 'cognitive impairment' encompasses a wide range of conditions including learning disabilities such as dyslexia and dyscalculia, dementia, autism, traumatic brain injury, brain damage following a stroke, attention deficit hyperactivity disorder (ADHD), emotional disabilities, mental retardation, cerebral palsy, and epilepsy. A learning disability is a reduced intellectual ability which affects someone for their whole life and occurs when the brain is still developing - before, during or soon after birth (Mencap, undated a). People with learning disabilities may have limited abilities with cognition, language, motor and social abilities (International Transport Forum, 2009). Some cognitive impairments such as dementia tend to occur in later life and are progressive. Dementia is a condition in which there is disturbance of some brain functions including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement (World Health Organization, undated). A cognitive impairment can affect the ability to understand, interpret and organise information and so may affect travelling. Not everybody with a cognitive impairment has difficulty in making a journey.

3. TRAVEL BY PEOPLE WITH MENTAL HEALTH CONDITIONS

Penfold et al. (2008) carried out in-depth interviews with 45 disabled people in a study for the Department for Transport on the travel behaviour, experiences and aspirations of disabled people. Nine of those surveyed had mental health support needs. None of the nine were employed, but some were involved in voluntary work and education. Some of them had caring responsibilities, including caring for disabled children. None of them drove their own car, but most of them were sometimes driven by others. The main modes that they used were public transport and walking. The sample included people with the following mental health conditions: anger management issues, bipolar disorder, clinical depression, generalised anxiety disorder, personality disorder, post traumatic stress disorder, and schizophrenia.

Some had fluctuations in the severity of their mental health support needs over time. During 'bad' periods travelling could be very difficult. But, the ability to travel was very important to enable them to access services and social networks. This was vital for their personal well-being. 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.

Confidence was a key factor in their experience of using transport. Three key factors were identified:

- **Routine and planning.** Familiarity with bus numbers, routes and times helped make journeys as stress free as possible. Having established routines with the minimum of disruption was extremely useful. The ability to plan trips was also important: for young people this meant using websites.
- **Safety and control.** This revolved around the choice of mode, having travel companions and the attitudes of staff. Sometimes when feeling very anxious some of the respondents could not use public transport and so perceived taxi as the only option. Sometimes travelling in confined spaces or at busy times could exacerbate feelings of anxiety and panic, so some modes were avoided, for example, the Underground. Having a companion reduced anxiety. Staff often seemed rude and unhelpful, for example, when offered a disabled concessionary travel pass. This issue partly arises because the disability is hidden.
- **Affordability and finance.** This is important because those being interviewed had low incomes because they were not employed. Hence having concessionary travel passes to enable them to use public transport free was very important.

The Mental Health Action Group (2011) undertook a survey of people with mental health issues through various relevant organisations. The survey

covered the need for public transport, the experience of public transport and concessionary travel passes. 203 responses were received from across the country.

A number of issues were identified in the survey. The availability of buses was an issue because the low frequency of services meant that many buses were overcrowded which made travelling difficult for many respondents. Journeys requiring changes were also particularly stressful. The lack of buses in the evening and at weekends in many areas led to social isolation for some respondents.

The cost of travel was an important issue. 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 had a pass (compared with 80% of older people). In some areas Dial-a-Ride was not available to people with mental health conditions unless they also had a physical health problem. Some respondents found it difficult to commit to a journey and so were unable to book rail tickets in advance and so could not buy the cheapest fares.

Many of the respondents liked electronic information because it provided reassurance; they also liked audio announcements as it could be difficult to read information if they are feeling unwell; information at bus stops is very useful but, for many people, it needs to be in large print and clear.

People with mental health difficulties are entitled to take advantage of the Passenger Assistance scheme (ATOC, undated) when travelling by rail, but many did not realise that they could request it. However, there were examples of people in the survey who had requested it, finding themselves being ignored by the staff member because the person requiring assistance did not look disabled.

SYSTRA (2014) carried out research into the travel requirements of older and disabled people for CENTRO, the West Midlands Passenger Executive. This included a group discussion with people with mental health problems.

Difficulty in accessing and understanding timetable and route information was a barrier to bus use with changes to bus routes and timings causing considerable anxiety to people with mental health problems. Some of the people had experienced bus drivers being unhelpful or unwilling to offer assistance, sometimes being deliberately rude or abusive. Another barrier to the use of buses was overcrowding as was the behaviour of other passengers. Other issues were people playing loud music (an issue particularly for people with schizophrenia) and concern about buses being late with no explanation. Some rail users appreciated having a toilet on board a train because this removed one of the anxieties about travelling. They also appreciated having consistent audio announcements, because it provided reassurance.

The House of Commons Transport Committee (2013) in its report on access to transport for disabled people noted some of the types of issue discussed above, particularly that people with mental health conditions may be affected by a lack of straightforward, easily accessible information on journeys which transcend local authority boundaries and different transport operators.

4. TRAVEL BY PEOPLE WITH COGNITIVE IMPAIRMENTS

The survey carried out for the West Midlands PTE by SYSTRA (2014) included discussions with two groups with learning disabilities. The bus was very important to the people in the two groups with some respondents saying that it was the only form of public transport that they could use independently, after receiving suitable travel training. They also used Ring and Ride (the local name for dial-a-ride) which some of them found invaluable because it meant that they could go out in the evening, as they were nervous about using the bus then. For similar reasons, some of them used taxis at night, although, in general they used taxis infrequently. The attitudes and behaviour of bus drivers presented significant problems for these travellers, particularly communicating clearly, especially by drivers whose first language was not English or those who did not have adequate knowledge of the bus route and the places along it. Some people found the drivers deliberately rude and abusive. Some were even taken advantage of by some drivers who overcharged them or failed to give the correct change. In other cases, drivers did not stop at request stops. Congestion on buses, particularly when it made boarding and alighting difficult, was another issue. The behaviour of other passengers often caused problems, including smoking, drug taking, playing loud music and bullying. Children in large groups shouting and banging on the bus were found to be frightening by some respondents. They sometimes made it difficult to get off the bus at the right time. Because the respondents with learning disabilities required travel training in which they memorised particular routes and times, when these were changed, they had to have further training to understand the changed routes or times. Buses running late, particularly in the evening, often led to taxis being used, despite the high cost. Some of the respondents had a pass giving them free off-peak travel, but often they did not fully understand the regulations and procedures, such as time restrictions on their use, where the boundary for free rail travel was, and how to renew their pass. Some people were not clear about the eligibility criteria for using the Ring and Ride service. Some of those who did use it found the drivers' attitude a problem, since they did not seem to understand the needs of people with learning disabilities.

Penfold et al. (2008) in their study of the travel behaviour, experiences and aspirations of disabled people for the Department for Transport conducted nine interviews with people with learning disabilities. Eight of the nine survey participants worked in supported employment and most of them lived in

supported accommodation. They travelled regularly to day centres to take part in social and learning activities and participated in a variety of leisure activities. They travelled on a daily basis using a variety of modes. Four enablers which underpinned travel by these people were: travel training, accessible transport information, a safe street environment and space on transport, and positive interactions with transport staff and other transport users. This list confirms the findings from the work by SYSTRA (2014) in the West Midlands. Travel training included not only learning the routes of journeys from end to end, safe crossing points, and bus stops, numbers and routes, but also training in 'keeping safe', learning how to cope with difficult situations arising from either the disruption of transport services or the behaviour or unwanted attention of others passengers and pedestrians. Usually this meant telephoning their support worker or speaking to transport staff.

Clear, reliable, concise and straightforward information was important to the people with learning disabilities in the survey by Penfold et al. (2008). Printed information needed to be in a clear, large font. Information received during the journey at bus stops and railway stations, both visual and audible, needed to be direct and to the point. This was particularly important when there was disruption to the service. Feeling safe and confident on the street and on public transport was very important. This included having safe crossing points near bus stops, having a seat on buses and trains and not feeling crowded by other passengers. Positive experiences of interacting with staff and other travellers made travelling a good experience

Alzheimer's Society (2013) describes how dementia affects the ability to travel. 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. A person with dementia may lose their driving licence so that will need to use public transport or transport provided by others. Minor assistance in the course of a journey, for example with ticket machines or understanding routes and timetables, may enable them to travel alone. Sometimes staff mistake the symptoms of dementia for alcohol intoxication. These issues are echoed in the presentation to the Community Transport Association Annual Conference by Chandaria and O'Hara (undated). They identified six ways in which accessing transport can be difficult for people with dementia:

- Frustration because the person with dementia hears and understands information but cannot get their body or brain to react to it;
- Poor balance and spatial awareness which means that the person with dementia goes into defence or flight mode when approached suddenly and is deemed as aggressive;
- Loud speaking from people thinking that the person with dementia is deaf whereas he or she did not understand the information given or the request made;

- Problems with perception and comprehension which makes it difficult to make an unfamiliar journey or cope with changes such as delays and cancellations;
- Because dementia is a hidden disability, it may not be apparent to others;
- People with dementia usually have to give up driving and so become more reliant on public transport.

Alzheimer's Society (undated) says 16% of respondents in a survey had to give up travel as a result of developing dementia. 14% said that they wanted better transport. People with dementia feel their biggest barriers to participating in their local area are:

- 69% lack of confidence
- 68% worried about becoming confused
- 60% getting lost
- 59% mobility difficulties
- 59% physical health
- 44% not wanting to be a burden
- 33% transport
- 33% lack of opportunity.

Crampton, Dean and Eley (2012) in their report on dementia-friendly York found some people with dementia and their families said that they will travel further if necessary to do their shopping where they are certain of friendly staff who will provide the necessary advice and help, where parking is straightforward and where the layout of the store makes it easy to find their way around. Getting lost is a fear and a reality for people with dementia which can reduce their confidence to travel around. The authors report 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 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.

Lamont, Kenyon and Lyons (2013) used focus groups to establish the travel issues for people with dyslexia. They held 6 focus groups with 52 people recruited through dyslexia support groups. Participants felt the main barriers to travel revolved around information. Learning was an important part of the 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. General problems encountered when travelling included:

- Listening linked with difficulty in processing the information at the same time;

- Numerical processing, for example, reading a bus number correctly;
- Reading, especially if the information was 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;
- Emotional effects, for example frustration, nervousness, lack of confidence and low self esteem, feelings of inferiority, confusion and embarrassment.

The following problems were found travelling by public transport by people with dyslexia:

- Auditory information which was too complex,
- Timetables which used unsuitable fonts, colour contrast, use of 24h clock, and so on,
- Electronic variable message signs, including scrolling,
- Web-based travel information, often because of the wealth of information,
- Obtaining information from other people, often caused by staff being unaware of the problems caused by dyslexia,
- On-board information. Problems driving: text-based directions e.g. in web-based journey planners, road maps (e.g. colour, fonts, too much information), road signs, satellite navigation systems (often very helpful).

The following were issues when driving with dyslexia:

- text-based directions, for example in web-based journey planners;
- road maps, for example colour, fonts, too much information;
- road signs;
- satellite navigation systems, but these could be very helpful.

Hunter-Zaworski and Hron (1999), in an American study about bus accessibility for people with cognitive impairments, carried out nine interviews: four of them were trainers of people with a range of physical and mental disabilities, four were co-ordinators of programmes for people with disabilities and one was a person with a brain injury. In addition, a survey was carried out with members of the Special Transportation Fund Advisory Committee of Lane Transit District in Eugene, Oregon. The conclusion from the interviews and survey was that human contact was the most important way of helping a person with cognitive impairments, with the most important source of information being the driver announcing the next stop. Having staff available was also very useful for defusing inappropriate solutions. Technology was not rated as a useful substitute for human contact. They concluded that staff

training should include ensuring that staff are comfortable serving people with cognitive disabilities and know how to offer appropriate help. Travel training on a one-to-one basis actually on the bus with repetition of the information was seen as the best technique to help get users started.

Rosenkvist et al. (2007) describe the four-year project carried out in Sweden on 'Accessibility in public transport for people with cognitive impairments'. There were two parts to the study. The method used in the first part was interviews with 27 experts who were occupational therapists, lay assessors and representatives from special interest groups. The second part involved semi-structured interviews and participant observation of public transport users with cognitive functional limitations. The research team 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 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, there is a risk of information overload which means that a traveller with cognitive impairments cannot sort out the relevant information. 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 find it difficult because they have communication difficulties and because they lack self-confidence.

Chan and Suen (2013) carried out a literature review about the issues involved in travelling by people with ADHD and learning disabilities. They argue that such people tend to be impatient, lack concentration and mental endurance and may not be able to react or respond promptly. They suggest that these symptoms, along with communication difficulties, may lead to confrontations with service providers and the public. The situation may be aggravated if they become disorientated and lost or unable to arrive at their destination on time. They cite evidence that suggests that young people with ADHD are more susceptible to pedestrian accidents than other children. They present two examples of 12 year olds in Canada who had confrontations with bus drivers. In one case the boy was threatened with bodily 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. The authors analysed the symptoms of ADHD and learning disabilities and make recommendations for governments, knowledge providers, especially transport

planners, service providers and users in terms of what should be done, what could be done and what should not be done.

Feeley (2014) used a similar approach to Chan and Suen (2013) to analyse the potential effects of 21 symptoms or behaviour of people with Autism Spectrum Disorder (ASD) on driving, using public transport, walking and cycling.

5. INTERVENTIONS TO IMPROVE TRAVEL FOR PEOPLE WITH MENTAL HEALTH CONDITIONS AND COGNITIVE IMPAIRMENTS

It is clear that travel by people with mental health conditions and cognitive impairments raises many complex issues. Many of these revolve around lack of confidence about finding the way, obtaining information, interacting with staff and other travellers, and coping with changes to the transport service. Hence it is necessary to provide ways of providing reassurance to travellers, either by providing information in appropriate formats or by offering access to people who are trained to assist.

Many transport authorities issue access guidance leaflets for disabled people. There are some that have been designed explicitly for people with cognitive impairments and mental health conditions such as the 'Travelling and getting out and about' guide issued by Mencap (undated c) and the 'Your Journey' guide issued by NEXUS (2014) which has been designed by local children with autism and Asperger's syndrome.

Travel training is a well-established way to give users confidence in travelling. It usually involves some classroom based tuition and then a practical element involving journeys accompanied by an experienced trainer. Schemes are often provided by organisations such as passenger transport executives, sometimes involving people with cognitive impairments in the design process. A similar idea is travel mentoring, such as that provided by Transport for London, where advice is provided on planning a journey using an accessible route and then a mentor accompanies the person for his or her first few journeys to help them gain confidence.

In order to provide good travel experiences for people with mental health conditions and cognitive impairments it is essential that staff have received appropriate training to understand their needs, know how to provide relevant information and advice in a suitable format and can assist in an emergency or when services are disrupted. All staff training needs to include awareness of hidden disabilities. Some schemes have been designed with input from local organisations such as the Northumberland Dementia Forums (Alzheimer's Society, 2015) and Blaenau Gwent Older Voices Group (Mencap, undated b).

A specific scheme to help disabled people is the Passenger Assistance scheme (ATOC, undated) which is a service provided by train companies to disabled passengers who require assistance with any part of their train journey. This includes helping to plan journeys, book tickets and make reservations; they also assist at stations and on board trains, with anything from changing platforms to finding a seat. More generally, it is important that there are staff available who can provide assistance at various points in the journey, particularly at points where decisions need to be made.

A useful concept is that of 'safe places' such as the Bradford Safe Place Scheme (SNOOP, undated) which entails the individual carrying a card containing the contact details of their carer which they can show to staff at places where the scheme logo is displayed. The trained staff provide suitable advice and can contact the person's carer.

6. CONCLUSIONS

This paper has shown that there are many barriers to travel for people with cognitive impairments and mental health conditions. A key issue is that they need to be given the confidence to make journeys. Having established routines with the minimum of disruption is very important. Confidence can be built up by various means such as travel training, providing good quality information and having trained staff available at critical points in journeys. It is important that the people with the various conditions are involved in the design processes of the various schemes.

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