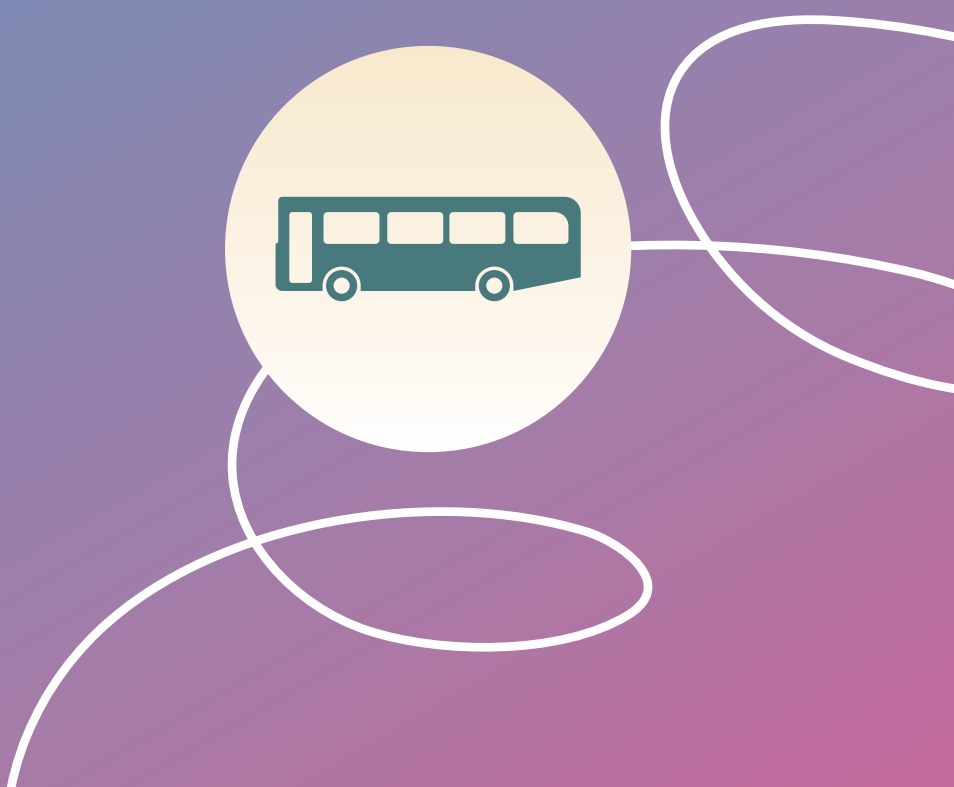


Mental Health and Transport

Summary report by
Alison Faulkner, Emma Ormerod, Jolie Goodman





About Motability

This project was funded by Motability, the national disability charity. The charity has oversight of the Motability Scheme, which enables a disabled person to use all or part of their higher rate mobility allowance to pay for the lease of a new car, scooter or powered wheelchair. The charity also provides grants directly to disabled beneficiaries, other charities and organisations, and is investing steadily in its innovation activities.

About this research

Motability awarded the Mental Health Foundation a User Research Grant to explore the accessibility needs of people with mental health difficulties when using transport. The research covers three themes: concerns for people with existing psychiatric diagnoses; the relationship between dementia, mental health, and transport; and transport and maternal mental health. This report concerns the first of these three themes, which was designed and delivered as a standalone piece of research while maintaining dialogue with researchers working on the other two themes.

Lead Researcher

Alison Faulkner is a survivor researcher, with many years' experience of working in mental health research. She has personal experience of mental distress and of using mental health services, and is passionate about using these experiences through her work.

Co-researchers

Alison worked with co-researchers Jolie Goodman, artist and survivor researcher and Emma Ormerod, survivor researcher, on the project. Emma helped to design the project and analysed the recruitment questionnaire. Jolie's role was primarily as creative advisor, bringing her design of graphics to the findings.

Advisory Group

An advisory group of seven people with experience of mental health difficulties and/or travel challenges advised and commented on several stages of the research and report.

Eleni Chambers

Survivor researcher, activist

Rachel Rowan Olive

Survivor researcher, artist and activist

Suzanne Collins

Service User Trainer

Lorna James

Sound Minds

Sandy Cudjoe

Sound Minds

Frances Grace

Sound Minds

Emma Mitchell

Neurodivergent Self Advocate

“When it is right, having transport, the ability to move around the world, is the most important thing. I would put it above relationships, or anything else”

Participant



ADULTS - MENTAL HEALTH + TRANSPORT

IN TRAINS THE ACCOUSTICS ARE WORSE THAN BUSES

SENSORY 1 2/11/22
MAINLY AUDITORY & SOME VISUAL

DREAD JOURNEYS USING PUBLIC TRANSPORT

MOVEMENT IN YOUR VISUAL FIELD

FOOT TAPPING

LOOK AT BOOK PHONE

MOVE AWAY OR LEAVE THE BUS

WILL WALK EVEN IN BAD WEATHER

BUILD IN SENSORY RECOVERY TIME TO SLOW DOWN

MY NARROW EAR CANAL AMPLIFIES SOUNDS

On the bus I sit with my LEFT EAR pressed to the window. At the top back left hand side of the bus.

LEFT HEARS BASS + FREQUENCY

RIGHT HEARS PITCH + TONE

HATED + ANXIETY OF SOUND

earbuds / headphones in playing LOUD LOUD MUSIC

WHITE NOISE WHITE NOISE NO PEACE + WORSE MENTAL HEALTH

Our approach

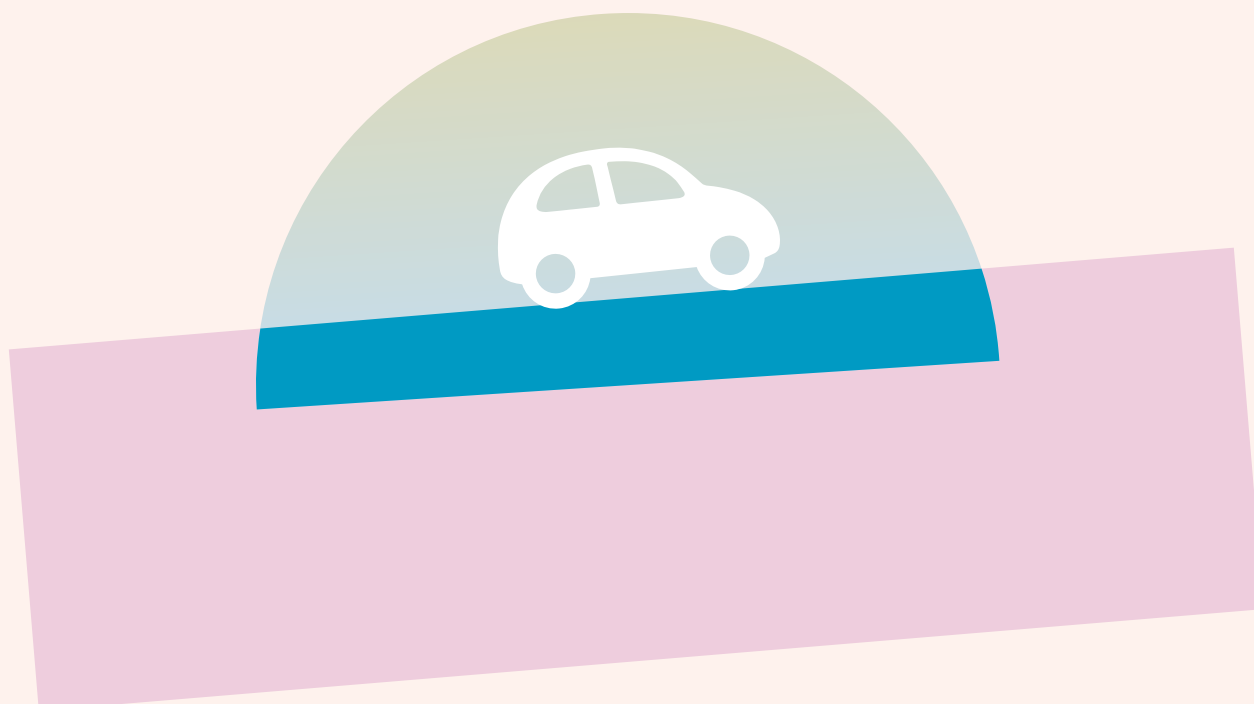
Aims of this study:

The aim of this study was to explore and reveal more about the role and value of transport for people living with mental health problems, as well as the barriers it presents and ways in which these barriers might be overcome.

We wanted to explore transport issues from the perspective of lived experience and also identify and articulate the intersectional issues facing people from marginalised communities. With this in mind, the researchers and the advisory group were all people with lived experience of mental distress, using mental health services and/or challenges with using public transport.

We carried out this work in three stages:

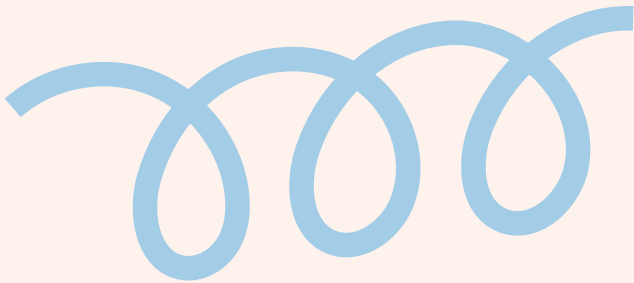
1. Recruitment questionnaire: asking key demographic questions and two questions about people's experiences of mental health and transport. This reached 76 people.
2. Interviews with 29 people selected from the 76 respondents to the questionnaire, supplemented with a few extra male interviewees.
3. Focus group with 7 people exploring transport and mental health issues as a group, both orally and with a creative element facilitated by Jolie Goodman.



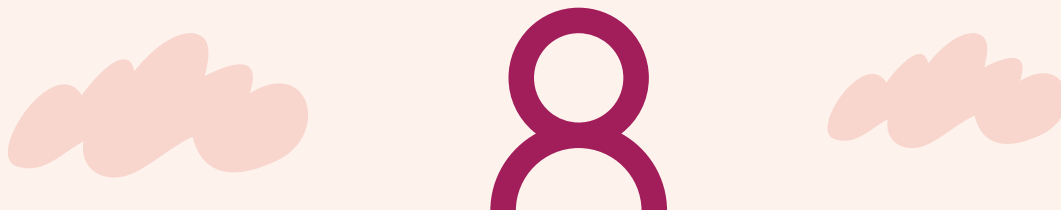
Findings

This research leads us to conclude that public transport is a vital lifeline for people with mental health conditions and neurodiverse people, but presents insurmountable barriers to many.

It can be a route to increased independence, to a social life and to essential health and social care appointments, but it can also be an overwhelming source of fear and anxiety. The implications of not doing anything to improve the situation are increased isolation, loneliness and poor mental health. The ability or capacity to travel in the world, as one of our participants pointed out, can bring joy and empowerment:



“It’s a lifeline. It defies the expectations we have for ourselves, it defies the expectations that other people have for us.”



The challenges

Anxiety

We wanted to explore transport issues from the perspective of lived experience and also identify and articulate the intersectional issues facing people from marginalised communities. With this in mind, the researchers and the advisory group were all people with lived experience of mental distress, using mental health services and/or challenges with using public transport.

People

Participants talked of being overwhelmed by the 'human churn' of public transport, particularly in dense urban areas and in the London underground, and in peak times such as rush hour and school times. Some people feared the unpredictability of others, that trouble might break out around them, particularly on buses; others feared being observed or stared at in public, and this was exacerbated by intersectional issues such as race and disability. Body weight or size also entered the frame, with people feeling anxious about the available space on crowded buses and trains.

Abuse and assault

Many people had experienced abuse on public transport: from rudeness and impatience of bus drivers and transport staff to the person having her crutches kicked from under her, to the people who experienced sexual assault, racism or

disablism in the public space. People did not feel safe, and were asking for ways of accessing help in situations where they were being targeted in some way.

Staff attitudes

Several people mentioned the attitudes of bus or taxi drivers and other transport staff, being rude, impatient or abusive and causing greater anxiety and distress for people already struggling to access transport. From many people we heard the plea for more kindness, training for transport staff and increased awareness – particularly of hidden disabilities.

Sensory overload

Sensory processing was a significant challenge for a number of people, who talked about the impact of sensory overload on their ability to use public transport. Most frequently this was about overwhelming noise of buses, trains and the London underground system. One person, who described their life as having been ruined by noise, had done a lot of research into sensory processing disorder and the associated diagnoses of misophonia and hyperacusis. Some also talked about the overwhelming amount and variability of visual information to process, particularly on large stations or when a journey goes wrong.

Space

People talked of the restricted space on buses and tubes, narrow seats and aisles and the discomfort of being forced into close proximity with other people. This had been exacerbated by Covid, meaning that some people feared physical contact. Several people wanted more single seats to be available. Equally, some people felt trapped on transport, more so on trains and the London underground, where it is hard to escape when panicking. Negotiating wheelchair space presented an additional challenge for people on buses and trains, as well as a barrier sometimes when trying to access taxis.

Access and accessibility

It can be a significant challenge for people with mental health difficulties and/or neurodiverse people to meet or negotiate eligibility criteria that would enable them to access travel concessions or support. It is also a challenge for people with hidden disabilities or conditions to feel socially comfortable about asking for help or to use priority seating, for example. Many felt that the sunflower lanyard – intended to notify staff of hidden disabilities – is poorly understood and needs to be more widely recognised.



1. Misophonia refers to the experience of strong emotional responses to sounds, commonly anxiety, anger, or irritation; hyperacusis is a condition when people experience the sounds of everyday life as intrusively loud or uncomfortable or even painful.

Negotiating the space: strategies and solutions

The interviews demonstrated remarkable persistence amongst the participants: finding many different personal strategies to enable them to travel and continue engaging with the world. Equally, they came up with practical suggestions for transport companies, local authorities and Government policies as well as ideas for voluntary sector and mental health services.

Independent travel

Some people were finding ways of travelling independently, whether by car, mobility scooter, bicycle or taxi. For some this was a choice, whereas others experienced it as a necessity. Driving, for example, was expensive – but for several people, the cost was worth it because it gave them control, independence and a safe space.

Technology

The use of headphones and smart phones were common strategies. Some people used noise cancelling headphones, others listened to music or played games on their phones to distract them from their surroundings.



Individual strategies

People often had favourite seats, or chose to sit near the exit or aisle. One or two people wore sunglasses as a screen to avoid eye contact and others chose to travel with a partner or friend to avoid being alone.

Advance planning

Planning a journey could take considerable time and effort – particularly if transport assistance was required. A couple of people referred to the huge amount of ‘invisible work’ done by disabled people to negotiate their daily lives. Some people printed out timetables and planned different routes as back-up should a journey go wrong. Many people picked their journey times with care, to avoid peak times and school times.

Peer support and collective action

Several people talked about the value of sharing strategies and learning from each other, whether through informal or more structured means. This gave rise to the suggestion for a website and App to be made available for people to access information and resources as well as share ideas and strategies.



Recommendations

We recommend further research to explore:

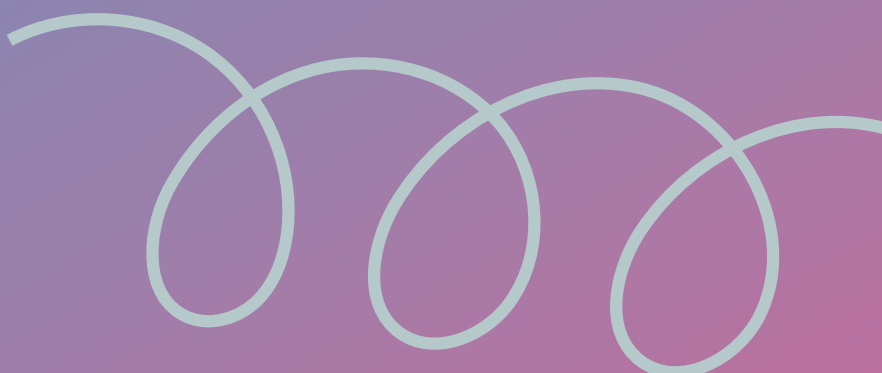
- Ways of designing transport to ameliorate some of the stressors, for example:
 - More flexible use of space, to accommodate wheelchairs and provide some single or more private seating;
 - Quieter trains and buses. (Electric buses have made a difference to some people and these are commended). The London underground system is particularly noisy, and it may be impossible to impact on this.
- Exploration and streamlining of the eligibility for the many different forms of travel assistance, free travel passes, etc.
- How to better address abuse and hate crime on public transport – and to make sources of help readily accessible to people.



Travel companies

The study highlights inconsistencies in awareness and training across the transport companies and their staff; and a general need to adopt an inclusive approach to hidden disabilities and to review safety measures for people experiencing abuse or assault.

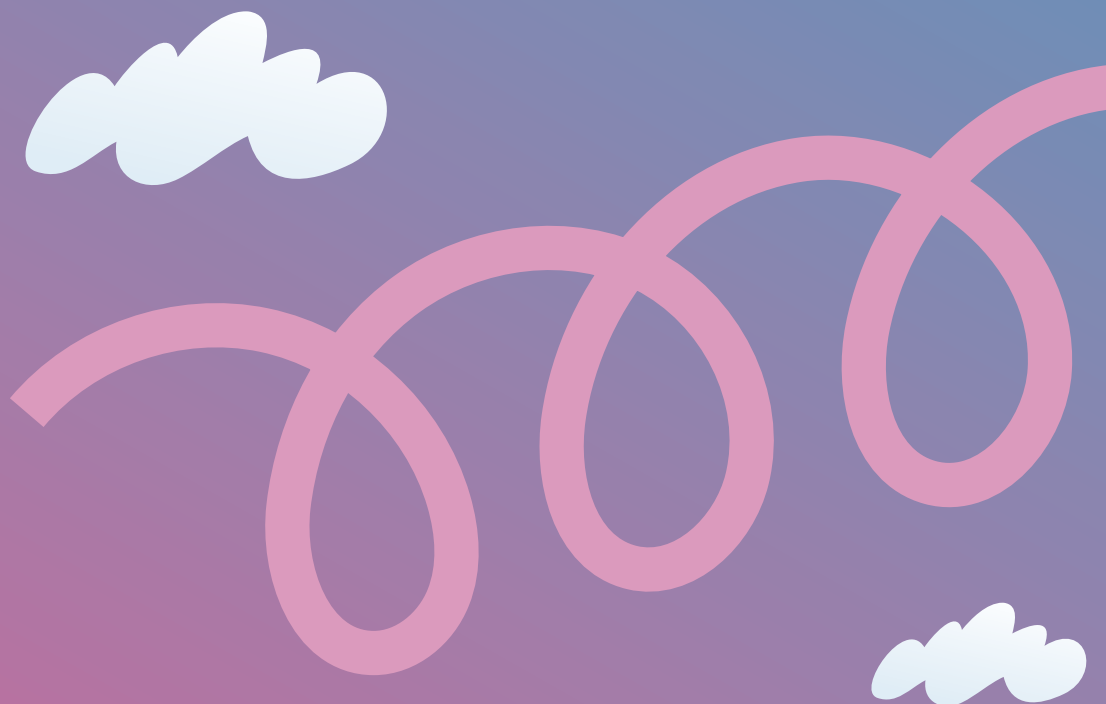
- Training for transport staff co-produced with people with lived experience of the challenges: to raise staff awareness of hidden disabilities and other conditions. For larger companies to make trained staff visible (e.g. badge/lanyard) so that people know who to approach.
- Adverts and/or announcements on trains and buses to draw attention to hidden disabilities and conditions that affect people's ability to stand and/or to understand journey changes and signage.
- Design of public transport: to pay special attention to noise; to consider co-design with disabled people to look at new and different uses of space.
- Rear entry on buses with card readers (for those who find the visibility of boarding the bus at the front challenging).
- Travel assistance and concessions for disabled people to explicitly include people with mental health and neurodivergent conditions.
- Communication around priority seating to explicitly include people with hidden disabilities and health conditions.
- To review their existing measures for passenger safety, to ensure that passengers with disabilities, neurodivergent and/or mental health conditions can access a source of help at all times on public transport if they feel unsafe.



Government / local and national

The study indicates a lack of awareness about both hidden disabilities and the sunflower lanyard. There are many ways in which these issues could be highlighted and brought to public attention. Equally, there are local policies that could be adopted at a national level to make it easier for people with hidden disabilities to travel. We recommend:

- Campaign to raise public awareness about hidden disabilities and conditions that might affect people's ability to travel, to stand on public transport and/or to communicate with others. This might include strengthening the role and purpose of the sunflower lanyard.
- Arrangements for taxi cards similar to those we discovered during this research, to subsidise taxi journeys for people who cannot use public transport.
- Raise awareness of the various ways in which people can already get support to travel, including accessing relevant benefits to enable them to do so. To bring this together in one space/website/ shared space that makes the information easily accessible.



Health and social care services, VCSE organisations

Health and social care services and VCSE (voluntary, community and social enterprise) organisations need to pay greater attention to the context surrounding a person's appointments, particularly where they know that the person experiences challenges in travelling. We recommend that:

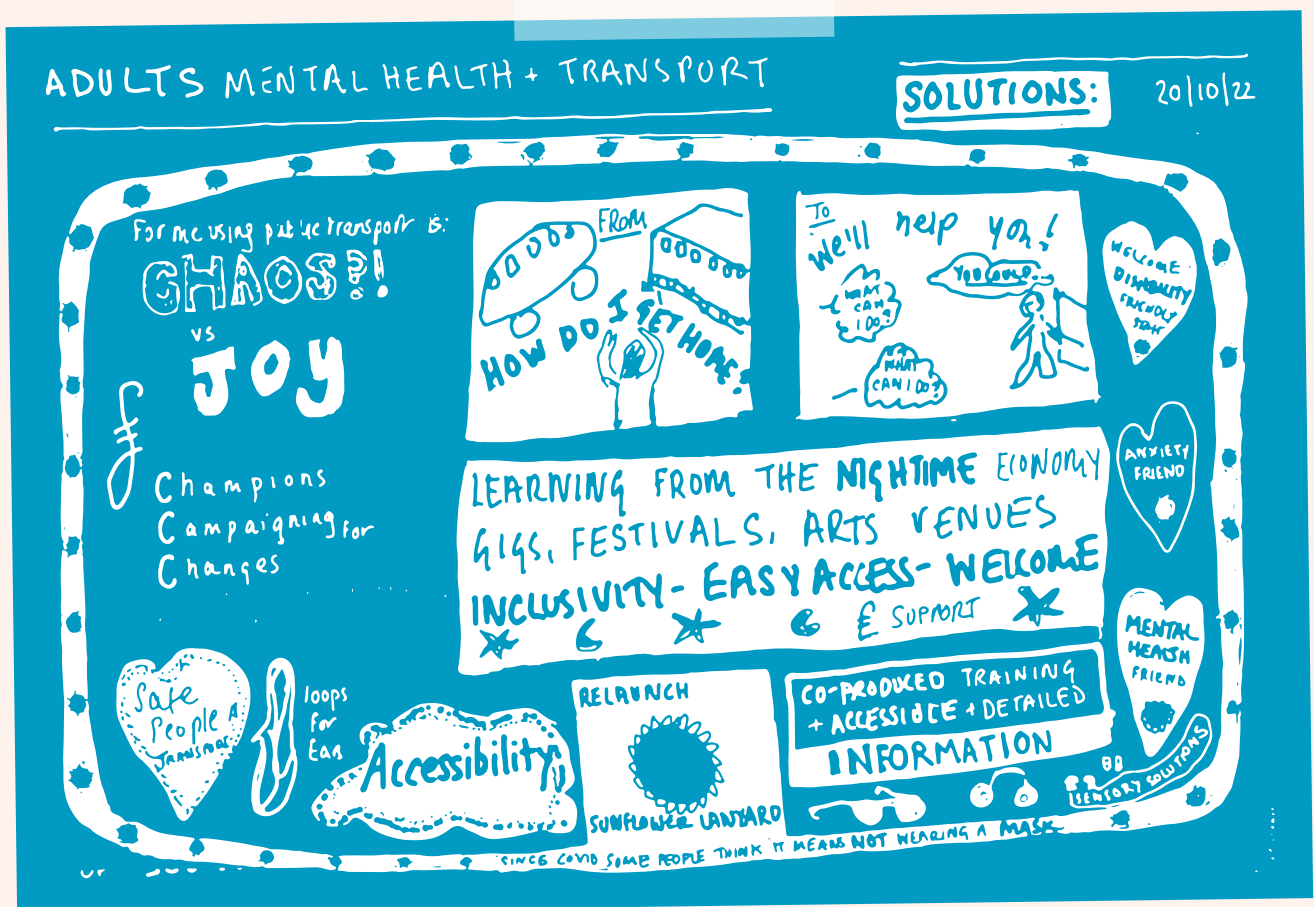
- Health and social care services, including VCSE organisations, to explore ways to support people to re-engage with public transport. This to include peer mentoring and peer support.
- VCSE or statutory organisations to consider developing a website for people to share tips and suggestions to support people in the use of public transport. This to include a space for people to share the range of strategies they use.
- Raise awareness / campaign to have neurodivergent and mental health conditions eligible for free travel passes and other travel assistance.
- Flexibility with appointments that renders the idea of arriving late less stressful – or responding positively to people who request appointments in the middle of the day. The maternal mental health report suggests a 'drop-in' window, which seems to be a positive way forward.

We would also like to suggest the production of short films/videos and the use of graphic representations – including those created during this project – to raise awareness of what it feels like for people with different mental health challenges and neurodivergent people to use, or try to use, public transport.



Examples of good practice

- One person had experience of a quiet room on a large railway station, and found it very helpful: Calm corner on Crewe Station.
- A few people had found the London Taxicard service valuable.







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