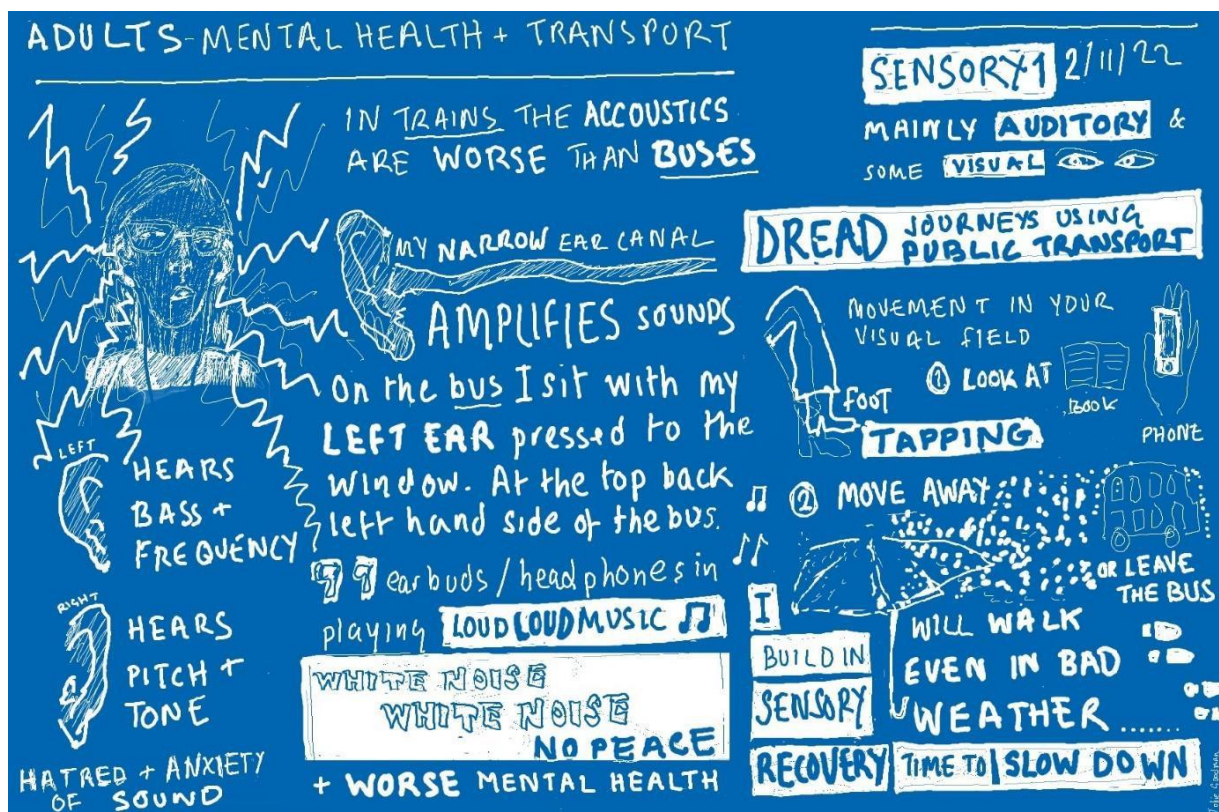


# Public Mental Health and Transport: the challenges and possibilities

A REPORT OF RESEARCH LED BY THE MENTAL HEALTH  
FOUNDATION AND FUNDED BY THE MOTABILITY FOUNDATION

By

Alison Faulkner, Jolie Goodman, Philly Hare, Rachael Litherland, Laura Richmond, David Crepaz-Keay and the people living with dementia, people with experience of mental health difficulties and mothers with experience of mental health difficulties involved in each of the three strands.



I think sometimes travelling, moving around in the world, is something people take for granted. But for a number of us, it's more than that. It's a lifeline. It defies the expectations we have for ourselves, it defies the expectations that other people have for us.

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*Graphics by Jolie Goodman*

*With grateful thanks to all those who took part in this research and shared their experiences.*

## INTRODUCTION

Research carried out by Mental Health Foundation and partners, funded by the Motability Foundation

In 2022, the Motability Foundation awarded the Mental Health Foundation a User Research Grant to explore the accessibility needs of people with mental health difficulties when using transport. The Mental Health Foundation contracted with partners to undertake three strands of research, exploring the challenges and possibilities facing: people with psychiatric diagnoses; people living with dementia; and mothers of babies and young children. All three strands were led by people with lived experience of the challenges under investigation. Working alongside all three strands was artist and survivor researcher Jolie Goodman, who created art works in collaboration with individuals and groups involved in the research.

In addition to these three strands of exploratory research, the Mental Health Foundation commissioned the market research company Opinium to include a series of questions in their survey of the general population.

This report gives an overview of these strands of work and an exploration of the common and different themes arising. For more detail on each of the strands, see the individual reports given in the Appendices.

## A BRIEF OUTLINE OF THE RESEARCH STRANDS

The three strands were undertaken somewhat differently (see appendices for the three full reports). The three groups of people are not mutually exclusive: people with mental health conditions can be mothers and any of us could develop dementia at some point in our lives. However, the groups were recruited with different emphases and were asked different questions.

### 1. People with diagnosed mental health conditions:

The aim of this strand was to explore the role and value of transport for people living with mental health problems, the barriers transport presents and ways in which these barriers might be overcome. We wanted to explore transport issues from the perspective of lived experience and 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. This was led by survivor researchers Alison Faulkner and Emma Ormerod, with an advisory group of eight people with lived experience.

#### *Respondents:*

Two-thirds of the interviewees described themselves as having long-term health conditions. Mental health and neurodivergent conditions or diagnoses included: anxiety, depression,

PTSD<sup>1</sup>, OCD<sup>2</sup>, autism/neurodiverse, borderline personality disorder, bipolar and psychosis. They were a diverse group in relation to sexuality, ethnicity and location but less so in relation to gender – very few men took part. Full demographic information is given in the main report.

*What we did:*

- Recruitment questionnaire with demographic questions plus 2 questions about people's experiences of mental health difficulties and their use of transport: 76 responses
- 29 interviews
- 1 focus group
- Involvement of the advisory group at every stage.

## 2. People with dementia:

This strand was led by Philly Hare and Rachael Litherland from Innovations in Dementia and co-produced with nine people living with dementia, who are part of the DEEP Network (DEEP stands for the Dementia Engagement and Empowerment Project – it is the UK network of dementia voices). They undertook a Dementia Enquirers approach to the research, which ensures people with dementia are in the driving seat of research. Their focus was on the impact of transport on the mental health of people with dementia, as the practicalities have been well researched.

*Respondents:*

Of the 40 people with dementia who responded, most (72%) were under 75.

*What we did:*

- Worked collaboratively throughout to shape the research
- A survey questionnaire: 40 responses
- Supplemented with data from a 'context review' to identify key evidence on the relationship between dementia, transport and mental health, in order to inform our strand.

## 3. Mothers of young children

The aim of this strand of the work was to explore the role and value of public transport for mothers and their babies/young children, as well as any challenges and ways that these might be mitigated or overcome. This strand took a predominantly qualitative approach. The research plan was designed in collaboration with partners and advisors, as were the research questions. It was led by Dr Laura Richmond, researcher and mother with lived experience of autism and complex PTSD.

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<sup>1</sup> Post Traumatic Stress Disorder

<sup>2</sup> Obsessive Compulsive Disorder

#### *Participants:*

All of the 30 participants were women (self-defined, trans inclusive), were based in England, were over the age of 16, had a baby (either naturally or through adoption or other means) in the last 5 years. Full demographic information is given in the full report.

#### *What we did:*

- Worked in partnership with advisors and organisations
- 12 interviews and
- 2 focus groups.
- Brief desktop literature review

#### 4. Opinium survey

A number of questions were put to the general population sample as context to the above research, including:

- How easy, or difficult, do you find planning a journey on public transport"?
- Are you aware that some people may have invisible disabilities meaning they need to take a priority seat?
- Would you know what to do to support someone who is having a panic attack on public transport?
- Do you think people with dementia have the right to travel on public transport independently?
- Do you know what the sunflower lanyard is?
- On public transport, how likely or unlikely are you to offer your seat to a mother with a baby or young child?

## FINDINGS

Here we give an overview of the findings: the common themes that emerged across the three strands and the different issues that distinguished the three groups of people.

First we consider the context provided by the Opinium survey.

#### 1. Context: The Opinium survey findings

- 20% of UK adults have difficulties planning a journey on public transport and using public transport. People with a disability are more likely to have difficulties, as are people living in rural areas.
- 83% of UK adults are aware that some people may have hidden disabilities; and a similar proportion would be willing to offer help to someone struggling on public transport.
- 45% would not know what to do to support someone having a panic attack on public transport.
- 44% of UK adults believe that people with dementia should have the right to travel on public transport independently.

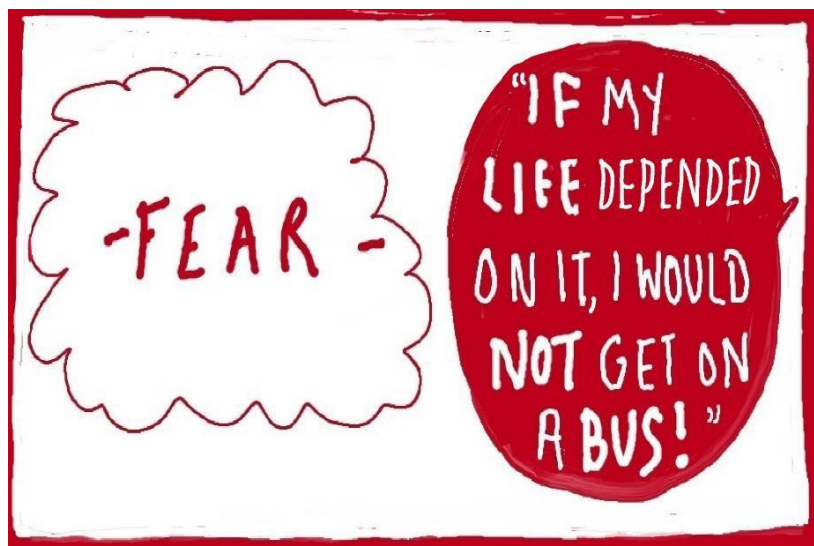
- 54% did not know about the sunflower lanyard.
- 84% said they would be likely to offer their seat to a mother with a baby or young child. People say they are more likely to respond to a crying child or toddler by offering a smile or sympathetic gesture or to ignore it so the mother doesn't feel embarrassed.

These results suggest a lack of awareness in the general public – particularly about the sunflower lanyard and about what to do if they encounter someone having a panic attack. Although most people are aware of people having hidden disabilities, there is still a fairly large proportion (17%) who say they are not aware and this is higher amongst 18-34 year olds (19%). Fewer than half (44%) support the idea of people with dementia travelling independently.

## 2. Common themes

One of the overarching conclusions reached by this research is that the complexity of different people's needs on public transport can compete with each other; it is unlikely that any form of transport can please everyone. More than anything, this emphasises the need for personalised forms of supporting access to transport. Nevertheless, some common themes emerged. Here, we pick out the most significant common themes (others include the unreliability of transport, cost and access in rural areas).

### 2.1 Barriers and challenges



#### *Anxiety*

A common theme across all three, anxiety had a plethora of underlying causes and triggers. However, the implications of severe anxiety about travelling were shared and could mean missed appointments and social opportunities, and profound isolation. The strand exploring the experiences of people with mental health difficulties identified the potentially disabling effects of anxiety. Some people attributed their anxiety to specific mental health difficulties,

such as complex PTSD, autism, psychosis. For example, one person feared that she would speak back to her voices on public transport and that this would cause difficulties with other passengers. Several people were anxious about being stared at, seen to be different or to be panicking, resulting in them feeling reluctant to wear the sunflower lanyard, for fear of being identifiably different.

*How do you make someone understand without having gone through it or just looks at you and thinks you're normal? [...] And we have to get past that - you're always looking around thinking, Do people notice that you're anxious? Can they see that you're getting hot? And stressing? They probably don't. But that's just the way we think.*

*I've got that little card that says, 'Please give me a seat' and that badge, but I just wouldn't wear it ... I think because I feel like I would be judged because I look absolutely fine.*

### *Space*

Space, and the competition for space, arose across all three; there was a general consensus about space being limited and contested. People talked of crowded buses and trains, competing over priority seats and spaces, and being forced to be in close proximity to other people. Wheelchair users and parents with buggies could be in conflict on buses, causing anxiety for both. Mothers, in particular, described the sharing of physical space as a major source of their stress on public transport, especially buses. They described insufficient space for prams and pushchairs as a key barrier and a cause of significant anxiety. People with dementia and people in wheelchairs also often found space on buses and trains limited and too narrow.

*When I'm waiting for a bus with the twins, I'm in an absolute state of anxiety about can I even get on the bus, what's going to happen, will there be conflict, will someone be angry with me if I ask them to move.*

### *People*

One of the ways in which space was a problem for people was the enforced closeness of other people, which could provoke anxiety for a number of reasons. Some were simply overwhelmed by crowds, 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. Others had personal experiences that made physical closeness with others intolerable.

*Because of an incident that happened a few years ago, I can't tolerate people in my personal space very easily. I cannot have someone sitting on the same seat.*

Some mothers, people with dementia and people with mental health difficulties feared the unpredictability of other people, expecting judgement or abuse, even assault. Mothers feared that their parenting would be judged, especially if their child was making a noise. They found that other passengers would sometimes stare, comment or give unsolicited advice. Both mothers and people with mental health difficulties described fearing that

passengers may be unpredictable or unsafe. Participants had experienced staring, stalking behaviour, rowdiness, drunkenness, and intimidation on public transport.

#### *Intersectional experiences*

Several people in the mental health and the maternal mental health strands talked of the additional challenges presented by being identifiably different on public transport. People described instances of racist abuse, disability hate crime, sexism, assault and fatphobic responses when on public transport. Although this was largely at the hands of the general public, there were instances of transport staff and taxi drivers being discriminatory and abusive. This inevitably created an additional reluctance to leave home and to face the potential onslaught of discrimination. Mothers of colour talked of their experience of being accused by bus drivers of fare-dodging as they boarded the bus with pushchairs.

*And I know it's on a regular pattern that if another person from their own race would enter the bus, they'd immediately move their belongings. And so I just stopped asking people, if the seat was spare, I would just stand.*



Women with past experience of sexual abuse could be triggered by the intrusion of their personal space in public.

*I've got a history of trauma and abuse intermittently throughout. I live in my threat system a lot of the time. I've got cPTSD<sup>3</sup>, I'm always sort of hyper-vigilant, shall we say, always thinking ten steps ahead to the worst possible outcome.*

#### *Attitudes of transport staff*

People in all three groups gave examples of transport staff being unhelpful, rude or abusive. All three strands recommended improved training for staff and greater staff presence.

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<sup>3</sup> Complex post traumatic stress disorder



Unhelpful or unfriendly staff was mentioned by people with dementia as one of the barriers to using public transport. Mothers found staff sometimes critical or hostile when they were trying to comply with requirements to fold buggies or to use card readers when struggling with buggies and children. The latter was particularly an issue for participants of colour, which was felt to be due to racism on the part of drivers. It was particularly challenging for those for whom English was not their first language so that they couldn't explain. This situation causes significant anxiety and distress. People with mental health difficulties and neurodivergent people also experienced staff being rude or impatient and causing greater anxiety and distress for people already struggling to access transport.

*Their customer service skills can be quite – I don't know how to put it – negative towards people. Because like, they're quite rude to people. They might not let you on the bus.*

Some people, particularly wheelchair users and people with buggies, had experienced outright discrimination from taxi drivers refusing to take them.

#### *Planning a journey*

The challenge of planning a journey was mentioned by many people in all three groups, supported by the Opinium survey which said that a substantial minority (20%) of UK adults struggle with planning their journeys. Several people talked of the effort, time and anxiety involved in planning their journeys. This affected people with children in buggies and people in wheelchairs, because of the possibility that they may be refused entry to a bus or train. However, many people talked of spending considerable time and effort planning a journey. Sometimes this was in order to avoid any uncertainty about getting to an appointment, to avoid times when buses or trains will be busy or to ensure access to assistance, toilets, food or other factors that make the journey easier. A couple of people referred to it as the 'invisible labour' required of disabled people.

*And there's a lot of extra planning with, like, the apps and the timetables and the connections, and you have to almost plan an entire set of routes, with back-up plans and street maps and all the rest of it just to get somewhere eight miles away.*

One aspect of planning a journey that all groups shared was the difficulty of accessing the right information, including finding out about accessible stations and reading timetables. We found that some people wanted to know which stations had flat access to the street via lifts and escalators, whilst others wanted to know if there were steps in order to avoid lifts and escalators.

#### *Sensory overload*

The overwhelming noise, visual information, smells and chaos on public transport was another common theme. It was raised by neurodivergent people in the strand exploring experiences of people with diagnosed mental health difficulties. It was raised by mothers overwhelmed by the physical and sensory demands on them when navigating public transport. People with dementia struggled with the cognitive challenges presented by signage and visual information particularly if a journey is changed. Noise was one of the major issues facing neurodivergent people and others experiencing anxiety.

*The biggest thing for me is probably the sort of sensory aspect. You know, like, going anywhere that's kind of crowded, or even just like has, you know, busy road or going to like a cafe is kind of not very possible, because I just get sort of, like sensory overload.*

#### *Health and social care appointments*

The struggle of getting to an array of health and social care appointments arose from people in all three groups. Unreliable transport services, uncertainty about getting on a bus with a buggy, and inflexible appointment times contributed to raised anxiety and worsening mental health for mothers with small children.

*It makes me feel so stressed and have anxiety. You feel like, when you go out, people are pushing you around. The station does not have lifts. It's unbearable if I have an appointment because I can't get there. I must plan how to get there, what to do with the kids, and I will probably be late, by five or ten minutes. I have anxiety and depression because of it and then am given medication, for my own mental wellbeing. I would rather just go to the places I need. It is very isolating.*

*[There's], I don't know, half a dozen buses a day. Not terribly convenient times, so that, for example, if you go to catch the bus that takes you to the bus station, to then get another bus to go to hospital, for example. There's big gaps of waiting around so that you can return to the village.*

## 2.2 Strategies

Two of the strands (mental health and dementia) explicitly asked people to identify the strategies they adopted to overcome the barriers they experienced. These demonstrated the resourcefulness of individuals and the value of finding ways of sharing tips and strategies through different platforms. The dementia strand concluded that it could reduce stress to plan ahead with an answer to the question “*What will I do if things go wrong on this journey.*” These are a few of the strategies shared with the researchers:

- Planning ahead: preparing timetables, journey alternatives, start early, take a phone number of someone to call for help.
- Travelling with a friend or relative.
- Headphones: play music, noise cancelling.
- Smart phone: play games or music to distract; use the Google Maps app to track the journey; apps that help with bus and train timetables.
- Having your destination written down.
- Choosing your seat with care.
- Shielding yourself from others by wearing sunglasses.
- Peer support or peer mentoring: people valued hearing hints and suggestions from others who faced similar struggles, and connected via peer support and social media as well as in face-to-face groups.
- Talk to other people.

### 2.3 The benefits of travel

People in all three groups talked of the benefits of travel and transport when it works well. It was described as a 'lifeline' by several people who valued the freedom and independence it offered. All three strands show that people depend upon public transport, and especially bus services, to access healthcare, amenities, and social support. A successful trip for people with dementia using public transport provoked a lot of positive feelings, such as happiness, relief and pride. Not being able to use public transport resulted in isolation and worsening mental health. The ability or capacity to travel in the world, as one of the mental health strand 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."

### 3. Differences

This is a selection of the differences that emerged between the groups.

#### *Practical barriers*

Although there were similarities, the practical challenges facing the different groups of people varied. Mothers travelling with buggies and small children, for example, faced considerable challenges in managing these (looking after children and pushchairs, access to changing facilities, breastfeeding in public to name but a few) whilst also managing the requirements of the mode of transport. People with sensory processing difficulties face the challenge of excess and distressing noise on transport, particularly on buses and London underground. People travelling in wheelchairs face the challenge of being able to access transport, being able to get on a bus or train and get off again at the right stop or station with assistance.

#### *Hidden disabilities and health conditions*

Some people with mental health difficulties were reluctant to be identified as having problems in public – indeed, the idea of wearing a badge or lanyard to demonstrate their difference and need for help was in itself distressing. This response was confirmed in a number of discussions, both with the advisory group and with another group of peer support workers in which the study was discussed.

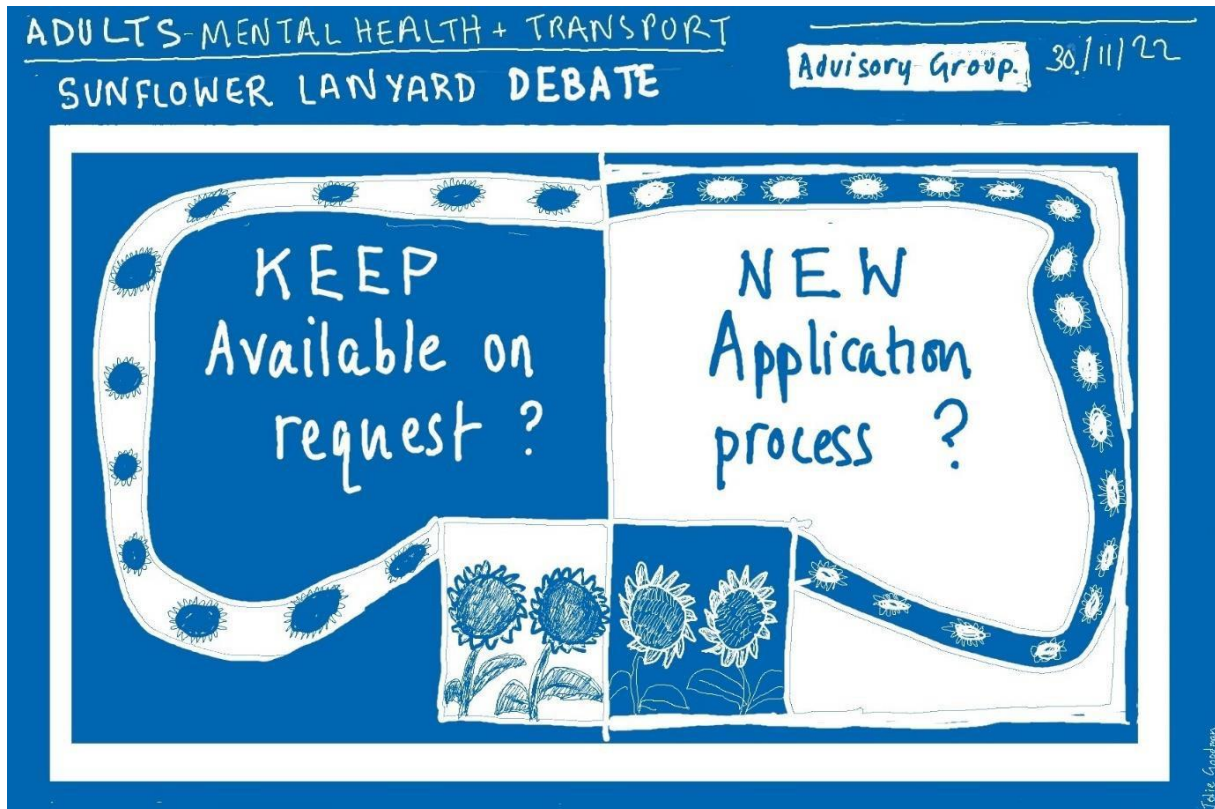
#### *Cognitive challenges*

People with dementia could find the task of planning and executing a journey to be a major cognitive challenge, particularly if the journey is altered mid-way for some reason. This was also a challenge for people with sensory processing difficulties and people with autism, for whom a changed journey, a cancellation or diversion, could cause considerable distress. Some people in both groups also struggled with communication which would make this situation more stressful.

#### *Sunflower lanyard*

Leading on from the above, the use of the sunflower lanyard came under considerable scrutiny. Some people had used it and found it unhelpful, some had found it helpful, and some had never come across it before. Several people mentioned that it had become

associated in some the minds of the general public with not wearing a mask during Covid. This emerges against the background of 54% of the general public not knowing about the sunflower lanyard, from the Opinium poll. There was some disagreement about how easy it should be to obtain a sunflower lanyard – whether you should be able to simply ask for one or go through a more formal application process in order to ensure that it retains its credibility.



## NEXT STEPS

All three reports detail recommendations that would make transport more accessible and passenger-friendly for the populations under consideration. They identify a mix of 'quick wins' and more complex systemic issues that would require investment. Here we pick out a few of the significant suggestions for next steps:

### *Further research*

- A wider exploration of the impact of different kinds of marginalisation on mothers' transport experiences;
- A quantitative study to establish which transport challenges are the most prevalent and detrimental to maternal mental health, and which solutions would have the greatest impact.
- Research to explore in more depth the challenges and benefits of transport for neurodivergent people.
- Better understanding of help-seeking, responses and initiatives that make it easier for people to ask for help.

- 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.

*Practical suggestions: quick wins*

- Card reader near the buggy and wheelchair space on buses
- Review of priority seating arrangements on buses and trains
- Seatbelts on some seats on buses.
- Signs and adverts on public transport to raise awareness of: hidden disabilities; breastfeeding being welcome; the sunflower lanyard, amongst other things.

*Practical suggestions: systemic*

- A transport charter for disabled people and a transport charter for parents (perhaps this could be one single charter for services to sign up to).
- Training for transport staff: co-produced with disabled people, people with mental health conditions and neurodivergent people.
- Review and refresh of timetables to make them more accessible to all, in collaboration with people with lived experience.
- Health and social care services to adopt flexible appointment times in order to reduce the stress of attending ‘all or nothing’ appointments. This could mean open or drop-in sessions or planning appointments to fit with people’s needs.
- A designated family carriage on trains.
- Introduction of more lifts at train stations.
- More staff available at train stations; with disability trained staff identifiable by a badge or lanyard.
- 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.
- Review and refresh of travel assistance policies and practices.
- Co-design of an ‘ideal’ bus together with disabled people and people with a range of mental health and other conditions.

*Public awareness*

- Review and re-establishment of the sunflower lanyard scheme for people with hidden disabilities
- Series of short films to show the challenges facing people with hidden disabilities, mental health conditions, neurodivergent people, mothers and people with dementia on public transport.