



# University of HUDDERSFIELD

## University of Huddersfield Repository

Heyman, Bob, Lavender, Elizabeth, Islam, Shahid, Adey, Alvin, Ramsay, Trevor and Taffs, Neil

The journey effect: how travel affects the experiences of mental health in-patient service-users and their families

### Original Citation

Heyman, Bob, Lavender, Elizabeth, Islam, Shahid, Adey, Alvin, Ramsay, Trevor and Taffs, Neil (2015) The journey effect: how travel affects the experiences of mental health in-patient service-users and their families. *Disability & Society*, 30 (6). pp. 880-895. ISSN 0968-7599

This version is available at <http://eprints.hud.ac.uk/25691/>

The University Repository is a digital collection of the research output of the University, available on Open Access. Copyright and Moral Rights for the items on this site are retained by the individual author and/or other copyright owners. Users may access full items free of charge; copies of full text items generally can be reproduced, displayed or performed and given to third parties in any format or medium for personal research or study, educational or not-for-profit purposes without prior permission or charge, provided:

- The authors, title and full bibliographic details is credited in any copy;
- A hyperlink and/or URL is included for the original metadata page; and
- The content is not changed in any way.

For more information, including our policy and submission procedure, please contact the Repository Team at: [E.mailbox@hud.ac.uk](mailto:E.mailbox@hud.ac.uk).

<http://eprints.hud.ac.uk/>

**THE JOURNEY EFFECT**  
**HOW TRAVEL AFFECTS THE EXPERIENCES OF MENTAL HEALTH IN-**  
**PATIENT SERVICE-USERS AND THEIR FAMILIES**

**Cover Sheet**

**Authors:** Bob Heyman, Elizabeth Lavender, Shahid Islam, Alvin Adey, Trevor Ramsay, Neil Taffs, and the Xplore Service-User and Carer Research Group

**Brief biographical details:** The research was initiated and managed by the mental health service-user/carer Research Group Xplore, which is hosted by the NHS Trust in which the project was located, in partnership with the University of Huddersfield. At the time when the research was undertaken, Bob Heyman was Professor of Health Care Risk Management, and Elizabeth Lavender a Consultant Research Fellow<sup>1</sup>, at the University of Huddersfield. Shahid Islam was Patient Experience Manager for the host NHS Trust. Alvin Adey, Trevor Ramsey and Neil Taffs are service-users/carer members of Xplore who have made significant individual contributions to the study discussed in this paper.

**Address where the work was carried out:** Institute for Research in Citizenship and Applied Human Sciences, University of Huddersfield, Queensgate, Huddersfield, HD1 3DH.

**Contact details for corresponding author:** Bob Heyman, 48 Beatty Avenue, Newcastle upon Tyne, NE2 3QP. Email: [B.Heyman@hud.ac.uk](mailto:B.Heyman@hud.ac.uk)

---

<sup>1</sup> Liz Lavender is now a research fellow at Bradford Institute of Health Research

**THE JOURNEY EFFECT**  
**HOW TRAVEL AFFECTS THE EXPERIENCES OF MENTAL HEALTH INPATIENT**  
**SERVICE-USERS AND THEIR FAMILIES**

This work was supported by a grant from The West Yorkshire Mental Health Research and Development Consortium.

## **ABSTRACT**

The qualitative study presented in this paper explored the perspectives of service-users, family members and staff about the impact of travel issues on the lives of mental health in-patients and carers. This topic was chosen because it was prioritised by members of Xplore, a service-user and carer research group, and has received little research attention. Travel problems were a significant issue for many service-users and carers, bound-up with mental health issues and the recovery experience. Travel facilitation through the funding of taxis and the provision of guides was greatly appreciated. A few service-users and carers positively valued distancing from their previous home environment. The meaning of travel issues could only be understood in the context of individuals' wider lives and relationships. The significance of the findings is discussed in relation to the social model of disability.

## **Keywords**

Mental health services  
Service-users  
Carers  
Participative research  
Travel issues  
Recovery

## **INTRODUCTION**

The study discussed in this paper offers a qualitative analysis of the impact of travel issues on mental health in-patient service-users and those who support them (carers). We aimed to identify the factors which led research participants to view journeys as easier or more difficult; and to explore perceptions about the impact of travel issues on life quality and the recovery process. In the Discussion section, the findings will be mapped onto a consideration of the spatio-temporal dimension of the social model of disability (Barnes, 1998; Shakespeare & Watson, 1997); and used to develop tentative recommendations for policy and practice in relation to an important but neglected issue.

As documented below, difficult journeys could cause considerable stress for both service-users and carers. In addition, service-users related mobility issues to their recovery in diverse ways. For example, Gemma believed that learning to travel independently would help her to develop control of her own life. In contrast, Diane would have preferred greater distance from her family because she considered her relationships with them to be part of the problem. Carers focused mainly on their own and the service-user's travel issues. But some felt that their own mobility affected their capacity to contribute to risk management or recovery for their relative. Cara tried to visit her son every day despite facing arduous journeys because she feared that he might commit suicide if she did not maintain this frequency of contact. Dilys, who could easily visit her husband by car, was concerned that his dementia would deteriorate unless she engaged him in daily activities such as going to the canteen.

People who are hospitalised for a period of time on account of mental health problems are distanced from their customary environment. The significance to the lives of service-users and carers of these shifts may not be immediately apparent to hospital staff who are 'presented' with large numbers of resident patients. Moreover, the impact of journey difficulty on in-patients and their families has received relatively little research attention. Most studies have been quantitative, concerned with the relationship between travel and treatment take-up. The '*distance effect*' on use of health services was first documented by Edward Jarvis (1850) who identified a negative correlation between home-hospital distance and admission rates. This effect has been widely documented for a range of services, including mental health (Zulian *et al.*, 2011; Higgs, 2009; Tseng *et al.*, 2008; Allard *et al.*, 2003; Fortney *et al.*, 1999). However, univariate designs confound distance with socio-demographic variables. Multivariate studies (Lovett *et al.*, 2002; Haynes *et al.* 1999) have demonstrated that a relationship between distance and service uptake exists even if such confounding variables are allowed for. Haynes *et al.* (1999) found a greater reduction in admission rates for mental health in-patient services (37%) compared with geriatric (23%) and elective surgery (17%), suggesting that access to the former is affected particularly strongly by travel issues. Chadwick *et al.* (2012) concluded from a review of nine studies that service-users themselves see distance as a barrier to accessing and using mental health in-patient services.

Loss of connectedness from home communities may impede recovery from mental health problems. A body of research has documented the contribution of social factors such as support networks, employment, living circumstances and homelessness, to mental health outcomes (Islam 2011; Tew *et al.* 2011; Curtis

2007), and the central role played by carers (Robinson et al. 2011; Repper, 2009; Happell, 2008). Journey difficulties may detach those who do use residential care from familiar support networks and 'safe havens' (Pinfold 2000).

As a result of service cuts, UK mental health in-patients are increasingly likely to be located further from their home residence (*Community Care*, 23<sup>rd</sup> April, 2013). The research discussed below contributes towards greater understanding of the consequences for in-patients and carers of such shifts in service delivery.

## **METHODOLOGY**

The study aim was to explore the impact, if any, of travel issues on the experiences of mental health in-patients and their carers. This topic was initially identified as a priority by service-user and carer members of the Xplore Research Group. Local concern had perhaps been heightened by a recent reconfiguration of services between two sites, one urban and one rural, located 11.5 miles apart. However, enquiries in a neighbouring local Trust indicated that similar issues can be identified elsewhere.

After the research protocol had been approved by a local NHS Research Ethics Committee, data collection was carried out between 2011 and 2013. An experienced researcher employed by the University of Huddersfield (Lavender) undertook the interviews, either individually or jointly with service-user Xplore members who were given qualitative research methods training. Sampling was designed to include current in-patients and associated carers who were likely to have experienced relatively easy and more difficult journeys between their home base and the hospital. These journeys were mostly to and from the two main Trust hospital sites, the urban Hospital 'X' and rural Hospital 'Z'. The two hospitals had a total of 150 beds and a staff establishment of about 200.

In order to preserve confidentiality, in-patients were identified via staff who were asked to approach individuals who met one of the two journey criteria. Those who were interested in discussing possible participation could contact the researchers via a stamped-addressed-envelope, email or telephone. Following a face-to-face discussion, those who agreed to be interviewed signed a consent form confirming that they understood that their participation was voluntary, that the interview would be audio-recorded and that they could withdraw from the study at any time. They also agreed to the researcher asking a staff member a screening question designed to ensure that it was safe for them to be involved in the research. Service-users were asked if they would consent to a person who supported them being asked to take part in the study. Those who agreed were asked to pass on an information pack to the person they nominated and a similar procedure for recruiting this person was undertaken. Service-users and carers were paid £10 for their participation in the research plus reasonable travel expenses.

In total, 11 in-patients were interviewed, 4 from Hospital X and 7 from Hospital Z. Of these 11 service-users, 4 were considered to have relatively easy, and 7 harder journeys between their usual residence and hospital in-patient location. It was only possible to recruit 3 carers associated with an interviewed service-user. Subsequently, 5 additional carers were recruited. Staff views were explored via a

single recorded focus group held in May 2013. The 7 attendees included hospital ward staff, occupational therapists, community psychiatric nurses and social workers, contacted through Trust staff networks. Interviews with service-users and carers and data analysis were undertaken concurrently until data saturation had been achieved, i.e. no new information was being generated. The subsequent staff focus group was used to obtain a service-provider perspective on the issues which had been identified.

Interviews with service-users and carers took 45-90 minutes to complete, and the staff focus group interview lasted for about 90 minutes. Lightly structured topic lists were used to guide discussions about interviewee perceptions of travel issues and their wider significance. After brief background questioning about previous experiences of mental health services, service-users and carers were asked about present and earlier travel between their home and in-patient facilities for themselves and for visitors. Staff focus group participants were invited to comment in general terms on the significance of travel issues for service quality and recovery, drawing on selected quotations from service-user and carer interviews.

Interview transcripts were analysed by one or more members of the Xplore research group using a shared thematic coding frame which evolved as the research continued. Data analysis was based on the principles of grounded theory set out by Strauss and Corbin (1990). The data were analysed in three overlapping stages of open, axial and selective coding. Open coding involved locating data items into one or more categories, for example for forms of journey difficulty. Axial coding was concerned with identifying properties of categories such as dimensional range, for instance in attitudes towards journey difficulties; and with mapping relationships between categories, for example between mobility mastery and recovery. Selective coding involved choosing a single category around which the entire analysis became focussed, in this case the management of travel issues in relation to participants' wider lives.

Emergent categories were tentatively validated through monthly meetings involving service-user, academic and health professional members of Xplore. The contribution of service-users was particularly valuable as they were able to relate research participants' comments to their own experiences. The overall analysis around the core category was assessed through the staff focus group, a stakeholder conference and informal interviews with service-users cared for at a neighbouring Trust. Those consulted strongly endorsed the key conclusion that travel issues can impact substantially on the lives of service-users and carers and on the recovery process.

## **FINDINGS**

The findings will be presented in two main sections. The first section focusses on what makes journeys seem easier or more arduous, whilst the second section explores the wider meaning of travel issues.

### **Journey Difficulty**

The material in this section has been organised around methods of transport. We will first explore the concerns which could arise even for those who had good personal

car access; then consider the use of taxis and public transport; and conclude by discussing the role of 'virtual' electronic travel.

### **Private transport**

Journey issues could arise even for families who possessed private transport, as discussed below. However, its availability often made travel to and from hospital unproblematic.

*Going back to just transport for a minute if I can, I mean for me that [visiting] isn't a problem because I drive and I have got a car. (Dilys, carer aged 60-65, wife of David aged 65-70, Hospital Z)*

Similarly, for service-users whose carers could transport them easily by car, travel between hospital and home was not an issue.

**Interviewer:** *So how do you get there, when you go home?*

**Respondent:** *[Husband] picks me up in the car ... He finishes earlier on a Wednesday, about three o'clock, so I just meet him in the car park. (Diane, service-user aged 30-35, Hospital Z)*

In this case, travel home for the service-user was particularly convenient because her family carer was able to fit collecting the service-user into his life-schedule. Ironically, Diane found this ease of access to be a mixed blessing because she sought to distance herself from family members in order to focus on her own mental health, as discussed in the second main section of the paper.

Although good access to a car mostly rendered travel unproblematic, some carers who owned cars did identify difficulty with journeys which they undertook frequently.

*Well it was [Kirsten's] choice [which hospital to be in]. I mean it's easier for us. I mean we've said all along, "It's the fact that it's half the distance to drive, but we're not bothered. We'll come and see you wherever, whatever". (Eric, carer aged 50-60, father of Kirsten aged 20-25, Hospital X)*

Problems with car travel could also arise in relation to a service-user's mental state.

*She was sectioned, but they couldn't provide any transport to take her there. And I wasn't very happy, sort of, because of the state she was in, to be driving alone in a car with her, so the next day she was picked up by an ambulance. (Andrew, carer aged 75-80, husband of Ava aged 65-70, Hospital Z)*

Although his wife was prone to violent outbursts, and had been sectioned, Andrew had been asked to drive her to hospital because no other transport was available. But he had declined because he was concerned that he would not be able to cope with her agitation whilst driving her to hospital, a 50 mile trip. Ava's retrospective account suggests that his fear was well-founded.

*Well I was quite worked up ... I was [laughs] completely out of the wilds of Africa, you know, and really very wildernessy - I am a wildernessy person by*



*nature ... But [laughs], the [ambulance] driver, his eyes were out on stalks [laughs]. (Ava, service-user aged 65-70, Hospital Z)*

Despite having to travel 50 miles each way to the two hospitals where his wife had been residing, Andrew did not find travelling to visit her particularly problematic. He did complain, as did other carers, about having to pay substantial parking charges for just collecting his wife. One carer with disabilities had experienced more serious parking problems.

*It's very difficult for me to visit ... If I can't park in the disabled, it's miles away [from the main car park]. I can't walk very far. It takes me ages sometimes to get in and out. (Harry, carer aged 60-65, father of Hannah aged 22, Hospital X)*

Thus, travel problems could arise even where private transport was readily available. The following sub-sections consider the issues which could arise for service-users and carers who relied on taxis and public transport.

### **Travel by taxi**

For many service-users and carers who did not have access to private transport, taxis were their preferred option, but cost was a barrier to their use. Gemma contrasted her ability to make short home visits by taxi from her present in-patient location with the unaffordability of doing so from a more distant hospital.

*So, it's doable, getting home from here [Hospital X] in a taxi. I can just about afford that. It's worth it to go off the ward for a few hours, but obviously in contrast to [Hospital Z], it seems a lot better. (Gemma, service-user aged 25-30, Hospital X)*

Ben, the only service-user who mentioned receiving a taxi allowance, used this funding to travel home.

*Sometimes I use buses, sometimes I use trains. But with getting a disability allowance, I get £70 a week for taxis, and I do use this money for taxis. (Ben, service-user aged 50-55, Hospital Z)*

In addition, he was given regular lifts by members of his assertive outreach team. Overall, he enjoyed an unusual level of support with respect to meeting his transport needs.

### **Public transport**

Although buses and trains was more affordable than taxis, many service-users and some carers felt unable to manage these forms of transport.

**Respondent:** *I wouldn't get on the bus.*

**Interviewer:** *Can you tell me why?*

**Respondent:** *I don't like all the people.*

**Interviewer:** *... So if you're not here in hospital, and you want to get about places?*

**Respondent:** *I have to get a taxi.* (Fay, service-user aged 25-30, Hospital X)

Callum indicated that his family did not visit him because they had no alternative to public transport, which they felt unable to cope with.

**Interviewer:** *Have you had any relatives visit?*

**Respondent:** *No, no.*

**Interviewer:** *Why do you think that is.*

**Respondent:** *Cos it's too far out to get someone visiting you ... Yeah, too difficult to find it as well.* (Callum, service-user aged 18-20, Hospital Z)

Members of the staff focus group considered that journey difficulty following relocation of some Trust in-patient services to a more distant site had become a significant problem for service-users and carers.

*It [travel difficulty] has a massive impact. It impacts on everybody. I think initially it impacts on the service-users, and the biggest complaint, or the biggest concern that they have - I shouldn't say complaint because it's a valid concern - is the fact that they are travelling two or three buses at a time ... And I can give you an example of an 80 year old man who was physically not too well, and he travelled every day to see his wife. It is sad to see that happen.* (Megan, staff focus group)

Some service-users and carers did use public transport even for complex journeys involving multiple changes, but could struggle to cope. A particularly serious problem was fitting long journeys to the fixed timings of visits and home leave. The interviewer helped the carer quoted below through the questions because English was not her first language, itself an issue with respect to managing public transport.

**Interviewer:** *But when he [son] was at [Hospital Z], you had to take three buses to get there?*

**Respondent:** *Yeah.*

**Interviewer:** *And how long did that take you?*

**Respondent:** *Oh goodness. Well, if I leave my home ten o'clock, I get there nearly two.*

**Interviewer:** *So, nearly four hours? It takes you nearly four hours to get there?*

**Respondent:** *Yeah, yeah.*

**Interviewer:** *Right. And then sometimes you went there, and you weren't allowed to see him?*

**Respondent:** *No.* (Cara, carer aged 65-70, mother of Charan aged 35-40, Hospital X)

Similarly, service-users could find that the length of journeys by public transport in relation to the permitted leave-time available precluded visits home.

*I've found it very hard just trying to get home, because when you get leave so many hours a day, it took that amount of leave just to get there on a train, to get there, never mind getting back and doing stuff at home.* (Jason, service-user aged 30-35, Hospital Z)

Helen regretted being unable to go home without preplanning her journey.

**Respondent:** *Those that live near can go home without warning, you know, like I used to do at [Hospital X]. I used to be up in morning and go home, home and back at 8 o'clock at night you know. They do the same here ... But I can't, 'cos I live so far away. For them it's easy.* (Helen, service-user aged 60-65, Hospital Z)

Her notion of living too far away was calibrated in relation to the demands of a manageable daily round-trip.

Some service-users who did use direct public transport ruled out undertaking complex journeys involving bus changes because they considered them too stressful or felt that they lacked the required navigational skills. Gemma would only contemplate bus travel which didn't involve changes, and assessed herself as not well enough to undertake even these journeys at the time of interview.

*I find getting the bus very stressful anyway, so unless it's one direct bus to somewhere - and, at the moment, I can't even do that.* (Gemma, service-user aged 25-30, Hospital X)

Jason was daunted by fear of getting lost in his new local town.

**Interviewer:** *Do you ever go into the centre of [Town A]?*

**Respondent:** *No.*

**Interviewer:** *... Why's that?*

**Respondent:** *Probably get lost for starters. I've only just found my way round [Town B].* (Jason, service-user aged 30-35, Hospital Z)

Such comments suggest that some service-users could benefit from support in using public transport, the issue discussed below.

### Guided public transport

Some service-users valued, or would have welcomed, being able to make accompanied train or bus journeys. Although reluctant to use buses on her own, Diane felt comfortable about travelling on public transport with a nurse 'guide'.

**Respondent:** *Well, I find that [solo bus travel] quite stressful. Really, just because of how I am at the moment and just because I've not got a bus for so long, I guess ...*

**Interviewer:** *So how would it be if you had to do that without the nurse's help?*

**Respondent:** *I wouldn't do it. I find it too stressful.* (Diane, service-user, age 30-35, Hospital Z)

Similarly, Ezra felt that family members would need initial navigational support in order to be able to visit him in hospital via public transport.

*He's saying that ... [his daughters] have got the offer of having a lift. That's really good because it will give his daughters an idea where [hospital] is, and*

*how long the distance is, and for the next visit it will help them plan. They'll probably come back by public transport, so it'll give them a good idea of the distance and what they'll need to do in order to prepare for it via public transport.* (Translator for Ezra, service-user aged 65-70, Hospital X)

Ezra felt that being driven to hospital would enable his daughters to develop a mental map of the hospital location in relation to where they lived, and thereby help them to manage subsequent complex journeys by public transport.

### **Virtual 'travel'**

Service-users and carers could draw on phones, texts and the internet to complement or substitute for visits. Cara reported that her son rang her four times per day at specific times.

*He ring every morning, eight o'clock ... Then he ring half-past twelve ... Then ring half-past five, then in the evening, [and then at] ten [o'clock].* (Cara, carer aged 65-70, mother of Charan aged 35-40, Hospital X)

Mother and son were both worried about the other's well-being, Cara with respect to Charan's personal safety, diet and hygiene, and Charan in relation to Cara's physical health problems.

Phone conversations served mostly as a means for maintaining contact with family and friends. Helen appreciated calls from family members which helped her to maintain relationships between visits.

*I look forward to me visitors, or, like, someone ringing up on the phone to see how you are. And that helps, it does, it does ... I'll ring tonight to see how she [dog] is and how they [family] are, and that.* (Helen, service-user aged 60-65, Hospital Z)

Although phone contact was valued, mostly as a complement to face-to-face contact, respondents also identified its limitations.

**Respondent:** *I ring them [family] often, over the phone, and stuff like that.*

**Interviewer:** *So you have some sort of contact?*

**Respondent:** *Some sort of contact, yeah.*

**Interviewer:** *Is that good, is that enough, or is it just a bit frustrating?*

**Respondent:** *Bit frustrating cos you can't really - you want to just sit down with someone and have a chat. Over the phone ... it's difficult to have a chat.*

(Callum, service-user aged 18-20, Hospital Z)

Some service-users felt that the constraints of phone communication made it too daunting to be of use, and preferred texting

*Usually I just text people. I'm not one for talking on the phone. I get scared.* (Fay, service-user aged 25-30, Hospital X)

Gemma linked her ability to cope with phone conversations to how well she was feeling.

*So, at least having my phone here, I can text my friends, because there are days when I just don't want to talk to people. And I can at least send my Mum a text and say, "Having a bad day", you know, "I'm alright but please don't ring"; or send my friends a text to tell them that I am okay but I don't feel like talking. (Gemma, service-user aged 25-30, Hospital X)*

Gemma also found the internet useful for keeping in touch, but felt frustrated at the lack of access in her present location.

*I mentioned about the computers at [Hospital Z] ... It sounds silly, but a lot of my friends I keep in contact with on the internet. But not being able to use the internet in here [Hospital X] is quite disorientating in a way. Its something that I think could be really beneficial to people in here. (Gemma, service-user aged 25-30, Hospital X)*

Variation in access to electronic communication could cause distress, as conveyed by Gemma's use of the term 'disorienting'. She had also found that rules limiting mobile phone use had constricted her ability to keep in touch through this medium,

*You can have your mobile phone on this ward [in Hospital X]. But at [Hospital Z], you are not allowed your mobile phone hardly at all. If you want to send a text message, I had to be supervised whilst doing so. You could only use the phone in the corridor where everybody can hear you. (Gemma, service-user aged 25-30, Hospital X)*

Gemma's response brings out the importance to her of being able to make phone calls privately, without being overheard. Similarly, Helen, who didn't possess a mobile phone, expressed frustration that her access to the ward phone was limited and intermittent.

*I can get through, if they'll let me get through on the phone, I'll ring them [family]. (Helen, service-user aged 60-65, Hospital Z)*

The quotation conveys Helen's sense of powerlessness in relation to having to get permission to use the ward phone to contact her family.

### **Journeys in their Life Context**

Service-user and carer attitudes concerning journeys to and from hospital residential locations are bound up with the meanings which such travel has for them in their wider lives and relationships. Four issues which emerged from the data will be briefly documented below: minimising separation; patients reacquiring 'freedom of the locality' as a stage in the recovery process; carers taking an active treatment role; and maintaining therapeutic distance.

#### **Travel to minimise separation**

Being separated from one's wider life could itself cause considerable psychological distress.

*That's the first time, the first time I seen them [family] for ages while I've been in here ... It's been awful for everyone it has. It's me grandchildren I miss and everything, all sorts. It's been awful.* (Helen, service-user aged 65, Hospital Z)

Helen also expressed concern over the state of her home which had been left unoccupied whilst she was in hospital.

*If they can't [discharge me], I'll ask him if they can get somebody to go with me to [Town A] ... and seeing if me home's alright, and everything.* (Helen, service-user aged 65, Hospital Z)

As documented above, being accompanied on journeys provided a means for mitigating such unwanted separations. Gemma depicted a downward spiral in which being unable to return to the home which she shared with housemates compounded her fear that they would reject her permanently.

*So because I couldn't go home, I got scared of going home. I was terrified that my housemates didn't want to speak to me because I'd been causing chaos.* (Gemma, service-user aged 25-30, Hospital X)

The last two quotations both illustrate ways in which travel issues, separation from former life and mental health problems could compound each other.

### **Mobility contributing to recovery**

Jason valued daily outings as a means of structuring his daily life as a hospital resident.

**Interviewer:** *So getting out and about for you, how important is that?*

**Respondent:** *Very important. Just gives me something to focus on.* (Jason, service-user aged 30-35, Hospital Z)

Some service-users and carers saw increased contact with the world outside the hospital as a marker of progress towards recovery, although this symbolic interpretation of mobility enhancement could be contested. Gemma's psychiatrist had strongly encouraged her to go out on her own. She had resisted doing so, partly as a result of anxiety, but also because she had not resolved her alcohol problem. Nevertheless, she had come to accept that she was not going to recover until she had accomplished solo journeys.

*I'm aware that you've got to [go out independently on visits]. Otherwise, I am not going to get out of here. If I don't take some control, I am either going to end up going out completely unprepared, because I have got to leave at some point, or not being able to go out because I am not showing any inclination to get better.* (Gemma, service-user aged 25-30, Hospital X)

For this reason, she felt ambivalent about travel being organised for her.

*I think although in a way it could be helpful if there was transport laid on, in a way that's taking away the control, because me ordering that taxi, you know, phoning for that taxi, and getting that taxi myself, is a big part of me taking control of going out. (Gemma, service-user aged 25-30, Hospital X)*

In one case, it was possible to compare the perspectives of service-users and carers about the wider meanings of travel issues. This example demonstrates that they do not necessarily hold similar views. Kirsten's parents regarded her movement to a hospital closer to home as a sign of progress towards re-entry into the community.

*So it's her choice [to move to Hospital Z]. So I think the great thing for her is she feels as though she's halfway back home, which is really good. (Eric, carer aged 50-60, father of Kirsten aged 20-25, Hospital X)*

This interpretation conflated geographical proximity with recovery progress, perhaps because the former took the service-user nearer to their historic home territory. However, Kirsten, speaking with considerable hesitation, eventually challenged the above account of her motivation.

**Interviewer:** *You were just telling me a minute ago about how you'd quite like to be transferred to [Hospital Z] because it's a lot closer to home.*

**Respondent:** *... Well, actually, I just wanted a change of scenery. (Kirsten, service-user aged 20-25, Hospital X)*

Eric was aware of his daughter's perspective, which he found puzzling.

*She actually said something quite strange as well before the move ... Someone was asking her why she wanted to move, and one of the things she said [was] ... "Oh, I just fancy a change". (Eric, carer aged 50-60, father of Kirsten aged 20-25, Hospital X)*

Such divergences in accounts about the wider meaning of travel could be bound up with wider family dynamics. In this case, Kirsten's parents viewed her relocation closer to their home as a step towards recovery, whilst she aspired to developing independence.

### **Carers taking an active treatment role**

Some carers considered frequent contact with the service-user to be vitally important because it allowed them to update themselves over short time periods about their relative's health, and/or to monitor their care. Cara strove to see her son daily because she feared that he might kill himself.

**Interviewer:** *So it's easy for you to go to [Hospital X] but very difficult to get to [Hospital Z]?*

**Respondent:** *Oh, very difficult, yeah.*

**Interviewer:** *Were you trying to go to hospital to see him everyday at [Hospital Z]?*

**Respondent:** *Every day ... He says, "I kill myself. They kill myself. They're killing me." So my other son, he work in Ireland, he says, "Mum, you go there and sit down and see him, no cry front of him". ... I says, "Look, I just see my son is alive".* (Cara, carer aged 65-70, mother of Charan aged 35-40 Hospital X)

Dilys whose husband had developed dementia visited him nearly every day, partly because she considered that the service was not driving forward his rehabilitation.

*I feel if we are not even getting him out to take him to the canteen to have a drink, we are losing the option of bringing him home really, because we are not even keeping things that were okay before he went in still okay, you know.* (Dilys, carer aged 60-65, wife of David aged 65-70, Hospital Z)

### **Maintaining therapeutic distance**

A few research participants positively valued the social distance arising from their in-patient residence. Diane did not want to venture out.

**Interviewer:** *Are you able to go out much? ... Or do you tend to stay in the ward?*

**Respondent:** *It varies really. I can go out if I want to. But ..., for reasons, I choose not to.* (Diane, service-user aged 30-35, Hospital Z)

She also felt that she was too accessible to visits from her children.

**Interviewer:** *So how often do you see your children when you're here?*

**Respondent:** *Twice a week at the moment.*

**Interviewer:** *And how's that? Is it nice to see them?*

**Respondent:** *Well, they're part of the problem.* (Diane, service-user aged 30-35, Hospital Z)

Similarly, Eric, the father of Kirsten, challenged the assumption that distance was necessarily harmful to recovery.

*Where distance is great, like in our case, where there was no local alternative or something, there is a risk, isn't there, that people get transferred. So you know there's a kind of assumption distance is bad, and therefore distance needs to be shortened. And there might be some examples where doing that is actually not in the best interest of the ... patient.* (Eric, carer aged 50-60, father of Kirsten, aged 20-25, Hospital X)

This comment appears to contradict Eric's view, quoted above, that Kirsten moving closer to home would represent progress towards recovery and discharge. Thinking more generally than in the particular case of his daughter, he was, perhaps, challenging his own assumptions, also questioned by Kirsten.

Giles' parents had decided to curtail contact with him in order to see what impact such withdrawal would have on him.



**Interviewer:** *So going back to [Hospital A], when he was there, did you have any contact with him while he was there?*

**Respondent:** *We only went, only once, cos he were far away, because we wanted to leave him on his own for a - you know, see how it goes ... We did want to see him, but not like that ... He wouldn't talk to us. Because it were far away, and there's no point going there. (Gia, carer, aged 65-70, mother of Giles aged 30-35, Hospital A)*

Journey difficulty, a desire to trial therapeutic separation and their son's refusal to communicate had compounded into a reluctance to visit him. In consequence they had only seen him once in six weeks at the more distant location.

## **DISCUSSION**

This paper has explored travel issues identified by mental health in-patients, carers and staff, a topic prioritised by service-user and carer members of the Xplore research group. The research focus was thereby shaped by stakeholder concerns, and this process enabled a relatively neglected but important issue to be identified for investigation. In terms of Arnstein's (1969) eightfold ladder of citizen participation, the project operated at level six through full partnership between service-user and carer researchers, the supporting Trust and academics.

The findings can be mapped onto the social model of disability (Barnes, 1998; Shakespeare & Watson, 1997). As argued by Kitchin (1998, p. 344), the marginalisation of people with disabilities cannot be understood '*without an appreciation of the socio-spatial processes that reproduce social relations*'. Personal mobility limitations in modern environments predicated on the assumption of quick travel (Freund, 2001) create barriers to many forms of social participation, for example in relation to employment (Danieli and Wheeler, 2006), use of services (Dowling and Dolan, 2001), participation in higher education (Goode, 2007) and enjoyment of leisure facilities (Thompson and Emira, 2011).

The social model allows prevailing thinking about disability to be inverted, so that issues of personal mobility are reframed as shortcomings of transport systems (Zarb, 1995). Considering this issue in relation to mental health widens the scope of analyses which have mainly addressed mobility in terms of bodily and visual impairments. The present research findings have shown that lack of confidence and resources can also be powerful barriers to transport usage. Crucially, personal mobility limitations are embedded in two processes of social exclusion for people with mental health problems: firstly, the societal processes which have led to many services being spatially separated from large centres of population; and, secondly, socio-economic deprivation which operates as both a risk factor for, and a consequence of, disability. Such exclusion carries symbolic as well as practical significance (Freund, 2001). Conversely, regaining 'freedom of the locality' (Heyman, Huckle and Handyside, 1998) can be bound up with a sense of recovery.

Caution must always be exercised in generalising from a small-scale, locally based, qualitative study. The identified level of concern about travel problems may have been raised by specific local factors, including reactions to recent and ongoing service relocations in the host Trust. Journey difficulty will be affected by geography,

demography, personal resources and transport infrastructure. In this case, significant features included the location of the two main Trust residential sites in the centre of a medium-sized city and a rural area some distance away, the complexity of bus routes which required several changes, and high levels of relative socioeconomic deprivation. Respondent self-selection could have generated a bias towards those who were concerned about getting to and from hospital sites. However, the sampling strategy adopted was designed to recruit individuals who might be expected to experience easy as well as difficult journeys.

Staff who participated in the focus group understood the difficulties which could arise for both patients and family members from unwanted separation. Differences may be expected between the perspectives of those who undertake front-line care and management roles. This difference is cross-cut by variations between the frameworks of those who view mental health care through different professional lenses, for instance those of medicine, hospital and community nursing and occupational therapy (Shaw *et al.*, 2007). Nevertheless, the findings reflect an overall systemic disjuncture (Japp and Kusche, 2008) between the orientations of service-designers and those of patients and their families. Patients present themselves to hospital-based service-providers primarily as individuals needing treatment. From this perspective, service-users' wider lives tend to be unreflectively backgrounded, even rendered invisible. The socially organised interpretive framing which underpins this view of patients can easily be lost sight of. Patients and those who share their worlds with them have more direct and comprehensive views of their previous, present and future lives. They do not experience themselves as 'cases'. For them, hospital residence involves a separation, not always unwelcome, between their past and current socially situated selves. Although a similar dynamic affects in-patients with physical complaints, their situation differs in two respects. Firstly, their hospital stays tend to be for much shorter periods. Secondly, disruptions to the lives of mental health service-users directly affect the problems which healthcare is attempting to address.

The findings allow a number of significant practice and policy developments to be recommended for further consideration. Greater awareness of the meaning to patients and carers of separation from their previous lives could generate more rapid recoveries and enhance service quality. An exceptional but disturbing account was given by one carer, Cara, who travelled for several hours to see her son only to be told that visiting hours had finished. Some in-patients feared that separation from their former lives could result in irreversible damage. For example, Gemma worried that her housemates might reject her when she eventually returned home; and Helen was concerned that her empty house might deteriorate whilst unoccupied. The implications, not always negative, of placing patients far from their home residence need to be systematically considered. If location entailing a difficult journey is required on account of bed availability or service configuration, the consequences for patients and carers should be taken into account in individual care-planning. Service-users who found public transport stressful valued being able to afford taxis. Funding their provision might provide a highly cost-effective contribution to recovery<sup>i</sup>.

Several service-users mentioned that they valued, or would have valued, the availability of a 'guide' to accompany them on journeys which they presently found stressful. Expansion of this form of support might make a significant contribution to

recovery by helping patients to become more confident about their travel capability. Travel issues such as changing buses which many people find stressful may become daunting to individuals with mental health problems. Travel guidance and support for carers may facilitate contact and so contribute indirectly to recovery. Attempting to facilitate access to and from carers would also contribute to recognising their potentially invaluable role in the recovery process.

Finally, the important role of electronic media in enabling patients to sustain ongoing relationships should be recognised in policies and practice<sup>ii</sup>. Conversely, recent developments in 'telemental' (Simms, 2011) therapies offer alternatives, where and when appropriate, to hospital treatment. Even if this consideration has to be balanced against others such as safety and avoiding disruption to hospital routines, 'virtual travel' should be considered as an important tool for facilitating the recovery process.

## **REFERENCES**

- Allard, S.W., R.M. Tolman, D. and Rosen. 2003. Proximity to service providers and service utilization among welfare recipients: The interaction of place and race. *Journal of Policy Analysis and Management*. 22(4): 599-613.
- Arnstein, S.R. 1969. A ladder of citizen participation. *Journal of the American Institute of Planners*. 35 (4): 216-224.
- Barak, A., and J.M Grohol. 2011. Current and future trends in Internet-supported mental health interventions. *Journal of Technology in Human Services*. 29(3): 155-196.
- Barnes, C. 1998. The social model of disability: a sociological phenomenon ignored by sociologists. In: *The Disability Reader*, edited by T. Shakespeare. London: Cassell.
- Chadwick, A., C. Street, S. McAndrew, and M. Deacon. 2012. Minding our own bodies: Reviewing the literature regarding the perceptions of service users diagnosed with serious mental illness on barriers to accessing physical health care. *International Journal of Mental Health Nursing*. 21 (3): 211-219.
- Curtis, S. 2007. Socio-economic status and geographies of psychiatric inpatient service use. Places, provision, power and wellbeing. *Epidemiologia e Psichiatria Sociale*. 16 (1): 10-15.
- Danieli, A., and P. Wheeler. 2006. Employment policy and disabled people: old wine in new glasses?. *Disability & Society*. 21 (5): 485-498.
- Dowling, M., and L. Dolan. 2001. Families with children with disabilities-inequalities and the social model. *Disability & Society*. 16 (1): 21-35.
- Fortney, J., Rost, K., Zhang, M., and Warren, J. 1999. The impact of geographic accessibility on the intensity and quality of depression treatment. *Medical Care*. 37(9): 884-893.
- Freund, P. 2001. Bodies, disability and spaces: the social model and disabling spatial organisations. *Disability & Society*. 16 (5): 689-706.
- Goode, J. 2007. 'Managing' disability: Early experiences of university students with disabilities. *Disability & Society*. 22 (1): 35-48.
- Heyman B., S. Huckle and E.C. Handyside.1998. Freedom of the locality for people with learning difficulties. In *Risk, Health and Health Care: A Qualitative Approach*, edited by B. Heyman. London: Edward Arnold.

- Happell, B. 2008. Determining the effectiveness of mental health services from a consumer perspective: Part 1: Enhancing recovery. *International Journal of Mental Health Nursing*. 17 (2): 116-122.
- Haynes, R., G. Bentham, A. Lovett, and S. Gale. 1999. Effects of distances to hospital and GP surgery on hospital inpatient episodes, controlling for needs and provision. *Social Science and Medicine* 49 (3): 425-433.
- Higgs, G. 2009. The role of GIS for health utilization studies: literature review. *Health Service Outcomes Research Methods*. 9 (2): 84-99.
- Islam, S. 2011. Square pegs in round holes: the mental health needs of young adults and how well these are met by services – an explorative study. *Journal of Public Mental Health*. 10 (4): 211-224.
- Japp, K.P. and I. Kusche 2008. Systems theory and risk. In *Social Theories of Risk and Uncertainty*, edited by J.O. Zinn. Oxford: Blackwell.
- Jarvis, E. 1850. The influence of distance from and proximity to an insane hospital, on its use by any people. *Boston Medical and Surgical Journal*. 42 (11): 209-222.
- Kitchin, R. 1998. 'Out of place', 'knowing one's place': space, power and the exclusion of disabled people. *Disability & Society*. 13 (3): 343-356.
- Lovett, A., R. Haynes, G. Sünnerberg, and S. Gale. 2002. Car travel time and accessibility by bus to general practitioner services: a study using patient registers and GIS. *Social Science and Medicine*. 55 (1): 97-111.
- Pinfold, V. 2000. 'Building up safe havens... all around the world': users' experiences of living in the community with mental health problems. *Health and Place*. 6 (3): 201-212.
- Repper, J. 2009. Carers of people with mental health problems. In *Mental Health: From Policy to Practice*, edited by C. Brooker and J. Repper. London: Churchill Livingstone Elsevier.
- Robinson, C. A., D. Seddon, A. Krayner, Y. Tommis, A. Roberts, and B. Gray. 2011. *Supporting Carers for People with Mental Health Problems: Needs Assessment to Service Provision*. Bangor: Bangor University Press.
- Shakespeare, T. & N. Watson. 1997. Defending the social model. *Disability & Society*, 12 (2): 293-300.
- Shaw M., B. Heyman, L. Reynolds, J. Davies and P. Godin. 2007. Multidisciplinary teamwork in a UK regional secure mental health unit: a matter for negotiation? *Social Theory & Health*. 5 (4): 356-377.
- Simms, D.C., Gibson, K., and O'Donnell, S. 2011. To use or not to use: Clinicians' perceptions of telemental health. *Canadian Psychology*. 52(1): 41-51.
- Strauss, A., & J. Corbin. 1990. *Basics of Qualitative Research*. Newbury Park: Sage.
- Tew, J., S. Ramon, M. Slade, V. Bird, J. Melton, and C. Le Boutillier. 2012. Social factors and recovery from mental health difficulties: a review of the evidence. *British Journal of Social Work* 42 (3): 443-460.
- Thompson, D., and M. Emira. 2011. 'They say every child matters, but they don't': an investigation into parental and carer perceptions of access to leisure facilities and respite care for children and young people with Autistic Spectrum Disorder (ASD) or Attention Deficit, Hyperactivity Disorder (ADHD). *Disability & Society*. 26 (1): 65-78.
- Tseng, K., D. Hemenway, I. Kawachi, S.V. Subramanian, W.J. Chen. 2008. Travel distance and the use of inpatient care among patients with schizophrenia. *Administration and Policy in Mental Health Research*. 35 (5): 346-356.
- Zarb, G. 1995. Modeling the social model of disability. *Critical Public Health*. 6 (2): 21-29.

Zulian, G., Donisi, V., Secco, G., Pertile, R., Tansella, M., and Amaddeo, F. 2011. How are caseload and service utilisation of psychiatric services influenced by distance? A geographical approach to the study of community-based mental health services. *Social psychiatry and Psychiatric Epidemiology*, 46(9): 881-891.

---

<sup>i</sup> A Trust manager indicated that the host Trust had had to curtail expenditure on taxis for patients on account of escalating expense. Given severe resource constraints, service-providers cannot avoid making hard choices. However, a different view might be taken if personal mobility was seen as a major component of the recovery process.

<sup>ii</sup> We were advised that the Trust in which the research was located does allow mobile calls, subject to considerations about risk and disturbance to others. However, the accounts given by service-users suggested that this policy may be variably interpreted in practice.