UNIVERSAL DESIGN OF PUBLIC TRANSPORT SYSTEMS FOR PEOPLE WITH MENTAL HEALTH IMPAIRMENTS

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Abstract

Objective – In this project we have examined what barriers people with mental impairments have in relation to travel, what can be done to make it easier for them to travel, and if today's understanding of universal design includes people with mental impairments.

Background – People with mental health impairments travel less often than the rest of the population. Lack of access to public transport leads to social isolation and worsening of symptoms, while high access to public transport is important for recovery. As such, how can we plan to increase mobility for people with mental health impairments? The field of universal design has done a considerable amount with regards to public transit for people with physical impairments, but more knowledge is needed about how people with mental impairments experience public transport.

Research question – What barriers do people with mental health impairments meet along the transport chain? What practical solutions can be used to get more people with mental health impairments to use public transport? Do today's understandings of universal design include people with mental challenges?

Methods – Nine semi-structured qualitative interviews were carried out with people with different types of mental impairments (depression, anxiety, Asperger's and bipolar disorder). Informants included both genders and a range of age groups and came from both urban and rural areas of Norway.

Results – Today's understanding of universal design—as seen in public documents, policies, research and support from the government—largely includes people with physical rather than mental health impairments. The main barriers identified for people with mental impairments included crowded spaces, lack of information, availability/frequency, waiting time—especially in relation to journeys including several different modes of transport, economic barriers and lack of understanding from staff. The train was considered superior to other public transport modes by most of the informants. The ability to travel by car is essential to the wellbeing of several informants.

Conclusion – We found several physical design measures that can improve travel for people with mental health impairments, including sitting area design, transport mode design and design of information systems. Other measures that can improve travel experiences for people with mental impairments were also identified, including economic support, training of staff and higher frequency of departure. We should therefore broaden our understanding of universal design, and not look exclusively at physical design without considering other factors that also play a role in actual usage.

Keywords: Universal design | mental health | public transport

Background

People with mental health impairments travel less often than the rest of the population [1]. Lack of access to public transport can lead to social isolation and worsening of symptoms. 83 % of respondents with mental impairments in a quantitative (n = 203) UK study said that access to public transport was 'very important' to their mental health [2]. As universal design at a macro level is not just an approach to developing technical solutions but is, rather, a form of ethics [3]. There is a need to extend our conception of universal design and evaluate the types of barriers people with mental impairments is limited [4, 5]. Research, practical solutions and theoretic approaches concerning universal design have mainly focused on people with somatic impairments. Planners, designers and others working with public transport infrastructure have limited knowledge about mental health impairments [4]. Efforts to reduce barriers for people with impaired vision and physical illness often consist of technical solutions—for example, ramps—but these might not be as helpful for people with mental impairments.

The quantitative UK study mentioned above found a considerable number of barriers connected to participants use of public transport that were not directly linked to technical solutions [2]. These included cost, lack of understanding from service personnel, crowded buses/trains, lack of access to public transport in rural areas, lack of reliability and information about cancellations or delays, and stigma/discrimination. Penfold et al.'s (2008) qualitative study—also conducted in the UK—included interviews with people with mental health issues and their problems linked to transport and mobility [6]. All participants used either public transport or walking as their main mode of transport. The researchers found that self-confidence was a key factor in the participants' experience of the transport system, and they also identified three factors that were important with regards to participants' use of public transport. First, the ability to both plan the trip and potentially incorporate it into a routine was important—planning was especially important with regards to new routes, longer trips or travel requiring connections. Second, safety and control were important factors with regards to participants' ability to travel; this included mode of transport, traveling with a companion, attitudes of service personnel, and the ability to avoid rush hour traffic. Several participants felt that having an invisible impairment made it more difficult to get assistance. Finally, affordability and financial concerns played a large part in determining participants' mobility—this was related to the use of taxis, in particular, but also included participants' inability to drive their own cars.

Due to the extremely sparse number of studies done on mental health in relation to universal design, there is still a knowledge gap on how people with mental impairments travel and barriers related to use of public transport. Geographical context is very important when it comes to barriers related to transport, as transport systems differ greatly between countries. This is the first study not done in the UK that we are aware of. This study also includes people using car as their main mode of transport – which gives a slightly different perspective. This study also fills the knowledge gap on what measures that can be done to improve the public transportation system, as we asked the informants directly about this.

Methodology and research questions

The general public reports following problems in regard to public transport: low frequency, long travel time and journeys with many connections between modes of transport [7]. What barriers do people with mental health impairments meet along the public transport chain? What practical solutions can be used to get more people with mental health impairments to use public transport? Do today's understandings of universal design include people with mental challenges? To answer these questions, we have chosen to use a qualitative approach for several reasons. A qualitative approach is well-suited for research on topics that are underexplored, where flexibility and openness is required. This approach is especially suited both to the study of personal and sensitive subjects, and of vulnerable groups [8]. To answer our research questions, we conducted nine semi-structured interviews with individuals who had different psychological impairments: specifically, anxiety, depression, bipolar disorder and Asperger's. Our informants were recruited through local and national organizations for people with mental impairments.

Our aim was to have a variety of informants, since type of disease and severity can affect what kinds of barriers are experienced and what kinds of practical solutions can improve public transport for these individuals. The informants were from across Norway, around half of them living in cities. The youngest informant was 25 years old, and the oldest was above retirement age. The sample included more females than males, and most of them were unemployed - although some volunteered in different types of mental health organizations. Having people with different types of mental impairments could be a limitation, as it could be more difficult draw conclusions on types of barriers and practical solutions since different diagnosis might have very different types of problems. However, since this was an explorative study to find out if people with mental impairments are included in today's understanding of universal design, our goal was to get a variety of barriers. In retrospect, we found that barriers were similar across the different types of mental impairments, which is also an interesting finding.

We conducted semi-structured interviews over phone and did a thematic analysis of the answers. The themes were daily travel behaviour, main issues when traveling, coping strategies, how they perceived different parts of the journey and different modes of transport – including non-public transport. Finally, we asked for suggestions for improvement of the public transport system. We have not examined differences between diagnosis, social context, geographical location, gender etc.

Results

Do todays understanding of universal design include people with mental impairments?

The theoretical framework on universal design is equally suited for mental and physical impairments. This study is based on a relational approach where the interactions between the individual, social and material is in focus [3]. In this view, the impairment is something that can arise in confrontation with the transport system, even though one might function well in other situations. Therefore, it is possible to design the environment in such a way that people with impairments can increase their quality of life. As we will see there is a lot of practical solutions to physical, social, organizational and economic environment that can increase wellbeing when traveling with a mental impairment. We carried out a literature study to determine the extent of existing research on mental health and universal design and to answer the question as to whether today's understanding of universal design includes people with mental challenges¹. Research on mental health in relation to universal design and transport is very limited; we found 55 studies², of which only 2 were relevant for our purpose [2, 6]. We also conducted a review of Norwegian public documents used as guidelines for universal design in transport and construction [9, 10]. These guidelines mainly focus on people with physical or visual disabilities. Financial politics also reflects the difference in "status" between mental and physical illness, where only 5 countries in Europe use more than 10 % of their health budget on mental illness [11], even though between 30-50 % of the adult population will get a mental illness during their lifetime [12, 13].

Barriers when traveling with mental health impairments

People with mental health impairments travel less than others [1]. In this study, informants reported that they travel from once a week to every day. The reasons for their trips are mainly to cover basic human needs: doctor's appointments, grocery shopping, social meetings, volunteer work and workouts. Only one informant is employed. Several informants expressed that they feel ambivalent when deciding between the stress of traveling and meeting their needs, and that they sometimes choose not to make travels due to the extra burden of the journey. For example, as one woman said, 'If I'm going somewhere and I must take the bus, I feel I use all my energy for the journey. When I have arrived, I have no energy left... as it is now, I only do things I have to'. Even though the informants experienced considerable anxiety when traveling, they all stated that having the opportunity to travel was very important for their mental health and for not feeling isolated.

We identified six types of barriers that our study informants encountered while traveling. The first barrier—one mentioned by all of them—involved crowded spaces and (dis)comfort. To avoid traveling in crowded situations, many of the informants chose to travel outside of peak hours. The two primary concerns here concerned finding it stressful to have people physically close to them, and not being able to find a place to sit. The lack of available seating was a problem in the actual transport vehicle (i.e., bus or tram), but also in the waiting areas. As one informant explained, 'If there is no place to sit down, then I must stand. Then I'm absolute sure I will faint, even though that has never happened'. One of the informants also mentioned that she fears sitting in the 'wrong seat'—for example, the seats reserved for people with physical impairments and the elderly. Many informants wished to sit by themselves, without someone in the seat next to them, and several expressed the need to sit in specific places. Where this specific place is located in the vehicle varies: for instance, one informant said he prefers sitting in the back, so he can have control of everything happening in front of him, while another prefers to sit in the front, so she does not have to see the other passengers. The informants reported that congestion was more of an issue on buses than trains. On the train, people usually do not stand in the aisle, and the seats with armrests make the seating areas seem more spacious; the first-class cars on the train were considered positively regarding physical design.

The second barrier that we identified involved the informants' ability to access reliable information. Real-time systems that state when the bus or train will arrive and how much time is left until an upcoming stop were considered very positively by all informants for whom this was available; those who did not have access to this kind of real-time system expressed the desire to have one in their area. The informants explained that the real-time system helps them feel like they have greater control over the journey and makes it so they do not have to be nervous about when to disembark. This system also enables them to be less dependent on asking others for help, which they explained could be mentally challenging. As one informant told us, 'The system has made it possible for me to use public transport. Without it I would struggle'. When the real-time system does not work as intended, however, it creates significant stress and insecurity. Solutions for special situations, such as a 'bus for train', can also be an extra burden when it comes to accessing information about where to go. A further issue with real-time systems raised by informants is that information that is not on screens can be difficult to find, as it is not standardized; moreover, they described that reading small text on complex information sheets can be very difficult when one is feeling stressed. In these situations, there may not be anyone around to ask for help, which compounds the difficulty.

Availability in terms of both frequency of, and distance to, public transport represents a third barrier. The distance between the informants' homes and transit access points ranged from a five-minute-walk to far enough away that travel by car is the only realistic option. The frequency of public transport for our informants varied from between every 5–10 minutes to twice per day; most had low availability in terms of frequency—with at least one hour between departures—which increased the need for other transport modes if something were to go awry. One informant explained it in the following way: 'I am dependent on a high frequency of public transport. If I'm going to take a bus in the morning and I don't manage to get on it due to anxiety, then my whole day is ruined. Therefore, I need to have a car'.

A fourth barrier with regards to using public transport involves (un)predictability and waiting time. It was important to the informants that the transport vehicles arrive as scheduled, and with no unpredictable stops during the journey.

¹We used the following words as search terms: transportation, architectural accessibility, environment design, concept formation, phobic disorders, anxiety disorders, universal design, transport, mental, anxiety, mental health, and public transportation. Nineteen databases were searched, including MEDLINE, Embase, PsychInfo, Sociological Abstracts, TRID, RIP, Transportation Sustainability Research Center, SWEMED, regjeringen.no, NORART, and DAAI. ²One study was unavailable.

Standing and waiting for the bus or walking a long distance to the station or stop was described as problematic for several of our informants, as this increases the time for them to think about their anxiety, and hence their stress levels increase. Direct routes or trips with minimal connections between different modes of transport also seem to be preferred by the informants. Long journeys with several modes of transport are particularly problematic. As one informant told us: 'I am not afraid of flying, but it's a very long process. I am not just taking the plane, I have to take the bus, train, airport bus, wait at the airport and travel on public transport again when I arrive at the other side'. The train was considered more predictable by many of the informants, as it cannot be stuck in traffic jams and its departure times are more exact.

Challenges within the informants' social environment represent a fifth barrier—these include challenges related to personnel, fellow passengers and travel assistance. All the informants travelled by themselves, for the most part, but wished to have assistance on certain trips. Several of our informants found that personnel working in public transport generally lacked knowledge about how to behave towards people with a mental illness. They were often described as being of no help and a source of stress. One of the informants told us that he felt like the personnel became somewhat aggressive if he did anything wrong with, e.g., the tickets. Another expressed her worry that the driver would have a negative tone in his voice, as this would make her feel more stressed. 1 of 3 drivers report that they do not have enough time to assist passengers [14], which is problematic for people with mental health issues, since they are already feeling insecure about the journey. Loud noises, drunk people or dogs that might seem threatening were also mentioned as problematic, but none of them had experienced stigmatizing behaviour from other passengers. However, an informant with an HC card³ has had people tell her that she is not allowed to park on the HC parking space—because they cannot see her impairments. The informants also mentioned that, in terms of service and assistance, it was better before everything became automatized. 'It was better before when you could buy coffee and tickets and go inside. Now it's just a machine and less human contact. I miss that [in relation to station area for the train]'.

Finally, financial barriers represent another important factor regarding the informants' use of public transport. Their economic situations affected not just more expensive travel, such as holiday trips, but also trips to volunteer work. The possibility of owning a car to increase personal freedom was also limited by finances for some of the informants, and one of the informants was forced to borrow money from her parents to be able to buy the 'long period' bus ticket (which is less expensive in the long run but requires more money up front). While it is possible to get financial aid in the form of a TT card⁴, the informants mentioned that it covers only some of the trips the informants would like to take to be able to participate in social life. In addition, several of the informants had never heard about TT cards. In general, the individuals we interviewed had the impression that is was more difficult to get financial aid for mental issues than physical illness, and in fact one of them had had their application for a TT card declined.

Differences between modes of transport

Most of the informants favoured the train over the bus, due to greater predictability, less crowding, higher comfort, rigid structure (as there is no unpredictable stops due to traffic jams etc.) and more seamless travel experience. Flying appeared to be the least-preferred mode of travel, even for the informants who did not have a fear of flying. The airport security screening was considered particularly stressful, due to the focus that is centred on one's person and the general fear of doing something wrong.

The informants who owned a car stated that this was important for their feelings of freedom; they explained that, without a car, they would sit at home more often. Two of the informants held HC cards, and they both said that before they had been given the cards, they were much more dependent on taxis and asking family and friends to drive them to different places. However, it is not easy to get an HC card for a mental impairment; one of the informants told us that she 'really had to fight to get it'—in fact, she was the first one in her municipality who obtained an HC card due to a mental health impairment. Having an HC card did not negate all transport-related challenges, however; as the other informant with an HC card explained, she has anxiety regarding parking inside, due to claustrophobia, and she is often very worried that there will be no available parking spaces, which would then force her to return home.

Measures to increase mobility for people with mental health impairments

The measures in this section is based upon the barriers mentioned by the informants and the informant's own requests for reducing problematic aspects of their travel.

	Barrier	Problem	Practical solution
Physical	Crowding	Standing on public transport	Having enough seating areas and ensuring
environment		and not having enough space	that some seats are screen from other. First
		between passengers	standard for design.

³A card that allows parking in spaces reserved for those with impairments, free parking on public parking spaces and extended parking time where there are limitations on parking time

⁴A card that covers a certain amount of taxi travels a year. Only available for people who cannot use public transport on their own

	Barrier	Problem	Practical solution
	Crowding	Seating areas reserved for people with impairments are viewed as areas for the elderly and those with physical impairments only; and only exist in the front of the vehicle	Expand the number of disabled seats, locate seating areas both in the back and front of the bus and provide more information to the public explaining that the seats are also for people with 'invisible' impairments
	Crowding	Not enough seats in the station area/stop	Ensure seating area on all stops / stations
	Information	Lack of information and difficult to find information in new places and between different modes of transport	Realtime systems, standardization of information systems/design, integrated systems between different modes of transport and travel companies
Social environment	Information	Difficulties related to using technology-based information and i.e., buying tickets using technology	Available personnel for assistance
	Social environment	Not enough knowledge about mental impairments among transport personnel.	Include information about mental impairments in first-aid courses and education of drivers.
	Social environment	Difficulties related to asking for help	"Need-for-assistance card" to make it easier to contact personnel and also inform the personnel how to make it easier for the person in need of assistance.
	Social environment	Not being able to travel alone	Available assistance for the whole journey as a potential strategy to help the individual make the same trip by themselves in the future
Organizational environment	Availability	Some areas have very limited access to public transport and makes using a car the only possible alternative	Alternative options of transport for areas with too few passengers to increase the frequency of public transport: making it easier to access HC cards with 'invisible' impairments and increasing the financial support provided via TT cards
	Waiting time	Increased stress related to waiting time between different modes of transport	Increase direct lines and reducing transit time between different modes of transport
Economic environment	Economy	TT-cards does not cover enough trips	Increase financial support on TT-cards
	Economy	Financial support differs between municipalities according to informants	Standardization of financial support (i.e., TT-cards) to reduce 'geographical discrimination'
	Economy	Not being able to participate in volunteer work due to financial situation	Reimbursements for individuals with impairments doing this kind of work
	Information	Several informants do not know what kind of financial help they are entitled to	Need to disseminate information about what types of measures exist to improve the mobility of people with mental health issues

Conclusion

If we compare our results with those of similar studies conducted in the UK [4, 5], we find many similar challenges in Norway. Through our interviews we identified six main barriers for using public transport related to physical, social, organizational and economic environment. Crowding was seen as a major barrier to traveling and many of those whom we interviewed chose to travel outside of peak hours to ensure they would be able to find a seat. Lack of information was presented as another barrier—however, in areas where real-time systems are available, the situation has improved. Our informants living in rural areas pointed to a third barrier: namely, that limited access and frequency makes it difficult to use this public transport. A fourth barrier centred around (un)predictability – delays, waiting time between connected routes, unpredicted stops increase anxiety. Social environment – lack of knowledge among drivers and lack of staff to ask for help was mentioned as a fifth barrier. Finally, and in keeping with Penfold et al.'s (2008) findings, the sixth barrier related to travel concerned the informants' economic situations, as several of them were unemployed, and some had been deemed ineligible for governmental support. It should be noted that, while we did find lack of understanding from personnel to be an issue, stigma from other passengers was not mentioned—this contrasts with findings from the British studies. However, one informant, who has an HC card allowing her to park in spaces reserved for those with impairments, reported being told by some people that she is not disabled and should not park in those spaces.

Even though a lot of the barriers reported from people with mental impairments can also be found to be important for the general population: crowding, need for information, high frequency etc. The extent to which these barriers affect the person traveling seems to be of greater importance when having a mental impairment. Lack of seating area might be annoying for the average traveller, but for a person with a mental impairment a lack of seating can lead to extreme anxiety – thinking one will faint if they do not find a seat. Proper information and not having to wait between different modes of transport is also something the average traveller would appreciate, but usually the average traveller will not have their whole day ruined or panic if they do not find information immediately or they must wait an extra 20 min for the bus to arrive. Having to deal with anxiety in every part of the journey can therefore result in choosing not to travel at all.

In this study, some of the informants used cars as their main mode of transport. For these individuals, having a car increased their freedom considerably and made it possible for them to live a more normal life. Some stated that, as they were unable to use public transport, if they did not have the HC card they would choose not to travel. This finding is especially relevant today, considering the current political debate regarding car-free zones in city centres. If public transport options do not include all travellers before measures to reduce car use are implemented, individuals like those in our study will be excluded from participation in important social settings.

Universal design has largely been limited to physical design and to considering people with physical rather than mental impairments. In our literature and document review, we found this to be the case in public documents, existing research and public discourse about the topic. Our interviews also confirmed that people with mental health issues must fight to receive public assistance, such as HC and TT cards. Findings demonstrate that universal design is more than just an approach to designing physical structure but is also an ethical principle to include everyone in the society. As such, there is a need to include other types of measures to increase people's mobility. We did find some physical measures—for example, the design of certain transport modes and information systems—to be important for people with mental impairments, but there is no point in having a physically 'perfect' system if some still cannot use it. Following our findings regarding social, organizational and economic environment, universal design needs be considered not just by architects and designers, but by drivers, those working in the transport sector, municipalities workers, and politicians. To do this efficiently and effectively, user perspectives from people with a wide range of impairments must be included; as mental illness is one of the most common health issues in modern society, planning for universal design must by necessity include people in this category. Of specific interest here is that several the measures we identified that would improve public transport for people with mental health issues would also improve travel for other disabled groups, and for the public in general.

This study has given us insight on barriers and possible solutions for people traveling with mental health related impairments. There is still a need for establishing what types of barriers are most widespread for people with mental impairments and how many people will benefit from the practical solutions mentioned by our informants. As this is a qualitative study, we will not get a representative selection, which is important to answer these types of questions and this calls for further research.

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