A public inconvenience

Title:

A Public Inconvenience: Better Toilets for Inclusive Travel - a human rights-based, coproduction study investigating toilet provision when travelling in Scotland for people with dementia and other physical and cognitive impairments

Authors:

Gillian Mathews, PhD, Research Fellow, E-CRED, Edinburgh -Centre for Research on the Experience of Dementia, School of Health in Social Science, University of Edinburgh
Orchid No. 0000-0002-0595-847

Mary Marshall, Professor Emeritus University of Stirling and Hon Prof, ECRED, University of Edinburgh, Dementia Centre, HammondCare UK

Heather Wilkinson, Professor, Director of E-CRED, School of Health in Social Science, University of Edinburgh
https://www.ed.ac.uk/health/research/centres/ecred

Orchid No. 0000-0003-0782-9746

Corresponding author:
Gillian Mathews,
E-CRED Edinburgh - Centre for Research on the Experience of Dementia, University of Edinburgh
School of Health in Social Science,
Room 3D.01
5 Forrest Hill,
Edinburgh
EH1 2QL

Tel: 07551361599
Email: g.mathews@ed.ac.uk

A PUBLIC
INCONVENIENCE
Better toilets for inclusive travel

https://toiletsandjourneys.wordpress.com
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https://www.youtube.com/playlist?list=PLewGw1aBfLCg8EpjdeKn9btceYCwCnepO

Abstract

This coproduced study drew on the United Nations Convention on the Rights of Persons with Disabilities to inform a Human Rights-based design. Using photographic images and reflective diaries, twelve participant co-researchers investigated the quality of public toilets when travelling in Scotland for people with dementia and other physical and cognitive impairments. Data were analysed using constant comparison and critically reflexive, group enquiry to produce contextualised evidence of toilet utility from the user perspective. Essential themes revealed major challenges associated with toilet accessibility, usability and design, emphasising the distressing sensory experience of the user when confronted with an inadequate or inaccessible toilet. Substantial overlap in needs was demonstrated but a few unique requirements aligned with specific disabilities were recorded for attention. Our findings highlight two key issues: 1) existing Standards are often unmet; 2) current Standards require review and endorsement by people who represent the full range of access needs.

Keywords: Public Toilets; Accessibility; Dementia; Physical and Cognitive Impairments; Human Rights; Coproduction

Main Text Introduction

For people living with dementia and other physical and cognitive impairments, the quality and accessibility of public toilet provision when travelling in the United Kingdom (UK) is a major issue. Many disabled people are excluded from journeying due to inadequate toilet design and facilities (Tales et al. 2017). Over 230,000 people in the UK require personal assistance to use the toilet but few of the standard accessible toilets meet these needs (Grant 2013). The private, sensitive nature of the topic means that it is not widely spoken about in actions to promote social inclusion (Marshall 2018). This leaves many people feeling frustrated, sad, angry and excluded due to an inability to enjoy activities that most of us take for granted (Slater and Jones 2018).

This Human Rights-based study contributes to the knowledge on accessible toilet provision and, as coproduced research, gives voice to seldom-heard groups on their personal experience of toilet use when travelling. It builds on earlier investigations, e.g. Hanson, Bichard, and Greed (2007); Slater and Jones (2018), that demonstrate meaningful public involvement in research of direct relevance to their lives. Further, it emphasises the continuing struggle of disabled people to attain equal citizenship and the ability to prosper in a society that does not discriminate on the basis of physical or cognitive impairment.

Scotland's Accessible Travel Framework (Transport Scotland 2016) acknowledges that accessible toilets are a fundamental aspect of Human Rights (HR), yet toilet provision for people whilst travelling continues to be a significant problem. Difficulties apply to transport hubs and different modes of travel with a failure to meet British Standards a common feature. There are two UK-wide standards, issued by the British Standards Institute (BSI), that affect toilet design in Scotland: BS6465 parts 1-4 and BS8300 (BSI 2020a, 2018). Despite no legal

obligation to meet these standards, compliance signals organisational diligence (BSI 2020b). For people with profound and multiple learning disabilities (PMLD), the Changing Places (CP) toilets campaign has been integral to developing a network of fully inclusive CP toilets that meet recommended standards (PAMIS, Promoting a More Inclusive Society 2017). As in England, CP toilets are now incorporated within Building Regulations (Scottish Government 2019). Regardless, CP toilets may not meet all the design requirements to be fully inclusive, including attending to the needs of those living with invisible disabilities such as dementia.

A Public Inconvenience: Better toilets for inclusive travel, was inspired by people living with dementia and other disabilities in Scotland who regularly encounter difficulties with toilet access whilst travelling. Researchers from the Edinburgh Centre for Research on the Experience of Dementia (ECRED) and community partners - DEEP (Dementia Engagement and Empowerment Project), the Dementia Centre, HammondCare, PAMIS, Upstream (explores the challenges of mobility and travelling with dementia) - worked alongside people with disabilities including dementia and other physical and cognitive impairments. Carers of people with PMLD were also involved. The project was funded by the Disability Research on Independent Living and Learning, a UK-wide research programme (DRILL 2015). DRILL supported projects that explored new ways of including disabled people as full citizens in society. The advancement of 'Disability rights', following the ratification of the United Nations Convention on the Rights of Persons with Disabilities (United Nations 2006), has positively impacted on the lives of disabled people, many of whom are often disabled by "social, attitudinal and architectural environments" (Milton 2015, p.17). Even though Human Rights-legislation is now an established means of highlighting the needs of disabled people, its application within the dementia context remains relatively new. The 'Rights-based' model can, however, offer a potent means to contest dominant medical discourses of dementia as

'deficit-based' or as a problem to be solved (Hughes and Williamson 2019). There is a risk, though, of the HR approach becoming too formulaic within the milieu of neo-liberal politics. A reliance on market forces can overlook the key structural factors, illuminated by the social model of disability, that impinge on the individual's salutogenic potential. The fusion of these two models offers a legislative-backed approach which emphasises the right to flourish with disability in an enabling society that recognises, respects and provides for the needs of all (Bigby, Frawley, and Ramcharan 2014, Berghs et al. 2019). An exemplar can be found in the Capabilities model which focuses on the individual's ability to exercise choice through experiencing substantial freedoms (Nussbaum 2007). In adopting a Rights-based approach within this study, we were conscious of human dignity and capacity for self-determination, points we return to in the discussion.

Our aim was to discover the everyday challenges faced by people with dementia and other disabilities needing to use a toilet whilst travelling. We specifically sought to: gather relevant data on transport-related toilet provision in Scotland; highlight key issues and make recommendations for inclusive toilet provision to transport industry policymakers, planners, and design specialists; stimulate high-profile debates on the importance of accessible toilet provision as an integral aspect of accessible transport.

Ethics

Ethical approval was given by the University of Edinburgh's Research Ethics Committee for Health and Social Science. Informed written consent was obtained from all the Participant Co-researchers (PCO) prior to taking part in the research. All the PCOs opted to have their names printed alongside the data they collected and gave permission to share data and

personal images for research dissemination purposes. The consent process was repeated twice more during the study at subsequent Gatherings. The PCOs received vouchers for a store of their choice as reimbursement for their time spent working on the project.

Research Process

Methodology/Research Design

The underpinning ethos for the study design was drawn from the Human Rights-based model of disability following the UN Convention on the Rights of Persons with Disabilities (CRPD)(UN General Assembly 2006, p.4). Article 1, in particular, highlights the importance of: *"Recognising that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others."* The research used a qualitative, co-production design, an inclusive approach that is increasingly adopted within disability studies, e.g. Pernia and Salmón (2020), Armstrong et al. (2019). We specifically used the photographic method based on the work and ethos of PhotoVoice, a charity that promotes the participatory and ethical use of photography for positive social change (Photovoice 2007). Participants take photographs in their local communities, critically discuss their data together, and then make active decisions on how to use these to advocate for policy change (Wang and Burris 1997, Povee, Bishop, and Roberts 2014). In this project, the practice of "purposeful inclusivity" (Hayes et al. 2018) enabled the involvement of people with different forms of cognitive and physical impairment and the carers of young people with PMLD. Bringing together people with different needs was significant to highlight the range of concerns being experienced in relation to travelling and toilet provision.

Research Aim

To identify the specific needs/key shared priorities that need to be addressed to enable people with dementia and other impairments to use toilet facilities while travelling.

Research Questions

1. What are the specific needs to be addressed to enable disabled people including those living with dementia to use toilet facilities during a journey including transport hubs, service stations, and on different modes of transport?

2. What are the key enablers and barriers to toilet use whilst travelling?

3. What are the shared priorities that transport policymakers, planners and service providers should focus on for designing accessible, easy to locate toilets that enable inclusive travel and participation?

The Gatherings

The study was conducted over eighteen months and structured across three phases, each punctuated by a 'Gathering'. The 'Gatherings' acted as critical events that brought together the PCOs and project partners at key junctures, to facilitate:

Gathering 1- information sharing, recruitment and PCO training (Month 3);

Gathering 2 - collective data analysis, preparing the knowledge exchange and impact plan (Month 10);

Gathering 3 - staging an event to disseminate findings (Month 15).

Gathering 1

A list of potential participants (refer Table 1) was generated from the networks of the project partners and all were contacted by someone with whom they already had an established relationship. Information on the project and the PCO role was communicated by phone or in person. Everyone who expressed an interest in being involved was invited to a first Gathering, and sent an information leaflet and a consent form. Two initial Gatherings were held in Aberdeen and Edinburgh to support recruitment across Scotland. Thirteen PCOs gave initial consent to take part. One carer did not participate due to time constraints. A further two (one person with dementia and one with a physical disability) left the study following the period of data collection (June – December 2018) but granted permission for their data to be included in the research.

Data Collection

Data were collected from city and rural locations around Scotland including airports, bus and railway stations and motorway service stations. Some PCOs included 'destinations' such as museums and cinemas as part of their data collection. This was particularly the case for the carers of people with PMLD who advised us that they rarely use public transport because of the widespread non-availability of Changing Places (CP) toilets. There are currently 220 CP toilets in Scotland and 1178 in England (Statistics obtained from PAMIS, October 2020). Availability varies across the different regions and not all council areas have one.

Data took the form of photographs, verbal recordings and/or short videos accompanied by written descriptions. The latter were encapsulated in photo-diaries which provided a standardised framework for data collection (Table 2 below). The PCOs captured elements of

toilet accessibility and design that were problematic and/or helpful to them, and described their felt experience of the toilets they encountered. As part of the process evaluation, a short interview on their experience of working on the project was conducted.

Photographs
The PCOs brought their own phones or cameras to the first Gathering. Training on how to photograph the different aspects of toilet provision was given, along with some suggestions on what to record. This included advice on taking images in public places, according due sensitivity in relation to data collection at different sites (including requesting permissions from relevant staff members and providing written information on the research project if, and when, required).

Over 1,000 photographs were created by the PCOs. These covered 86 locations across nine Scottish regions and included bus and rail stations and ferry and airport terminals. The photos provide a visual account of toilet provisions across Scotland and reflect each PCO's individual interpretation of the research questions based on their everyday journeys. Along with the textual reports, the photographic images help to situate and contextualise the unique experiential encounter of each PCO.

The Photo Diary
The diaries were designed to prompt PCO exploration and reflection on each toilet encounter from a range of perspectives. The textual data from the 78 diaries produced, illuminated and clarified the photographic content, giving descriptive narratives of their toilet experiences in respect of accessibility, design and functionality, and, sensory and emotional experience.

[Table 2 near here]

Data Organisation and Preliminary Analysis

Two members of the research team organised the data and undertook preliminary coding in preparation for group analysis at Gathering 2. This involved reflection on the research aim and questions followed by a stepped process facilitated by NVivo 11 software (QSR International 2015):

1) Looking at the Data – scrutinising all the visual images relating to each individual toilet encounter and close reading the linked photo-diary to gain an overall perspective of the PCO's experience and intentionality.

2) Primary classification of the data into broad categories, connecting PCO quotes to their photographs to convey their meaning and purpose.

3) Systematically searching the data, comparing and contrasting content to detect areas of commonality and difference, and to identify preliminary themes.

4) Refining the data into twelve thematic sets (signage, access, toilet layout, buttons, change machines, doors and locks, health and hygiene, noise, red cord, reflections, colour contrasts, taps) with accompanying quotes to help bring context to the PCO experiences.

5) Identifying examples from each theme, ensuring that work from all the PCOs was represented.

Gathering 2 provided an opportunity for all the PCOs to come together and compare their experiences as part of a group narrative. The analytical process offered a platform for the expression of feelings and concerns, and the opportunity to give comprehensive insights into notable aspects of their toilet encounters. The PCOs initially worked in interest-specific

groups — dementia, learning, and, physical disabilities, and carers of children and adults with PMLD. Each group included a member of the research team and a scribe recorded the main discussion points. The sets of themed photographs with quotes were discussed and reviewed within the group who reflected upon and shared their respective experiences. The individual groups agreed the three most important issues emerging from the data and selected the three photos (with quotes) that best signified these. The photos and principal discussion points from each group were then taken forward to the next stage of whole group analysis. This involved all the PCOs coming together to debate their key areas of concern and decide the priority themes to take forward as findings. The final part of Gathering 2 involved a conversation on potential formats for knowledge exchange and dissemination.

After Gathering 2, the project coordinator drew together the conclusions from the collective analysis. These were than shaped, with support from the research team members and various PCOs, into a range of outputs for dissemination purposes. The outputs were presented at Gathering 3, our launch event, and comprised: project report; policy brief; set of postcards with PCO biographies and quotes; a series of banners reflecting individual PCO contributions to the project; pledge cards; short video interviews with PCOs; a play written and developed by the PCOs in conjunction with a community-based theatre group. The latter offered a key opportunity for the PCOs to actively develop a key research output and directly represent their experiences to those who make policy decisions. The play was filmed during the launch and later divided into a series of short videos for the project website and social media: https://www.youtube.com/playlist?list=PLewGw1aBfLCg8EpjdeKn9btceYCwCnepO

Results

The main themes arising from the data concerned problems with: Accessing the toilet; Ease

of use; and Emotional distress. A further theme emphasised that, although most toilet needs

were in common, the PCOs identified a few differing and, sometimes conflicting needs.

[Table 3 near here]

Theme 1: Difficulties accessing the toilet

It can be hard to find, get in and get out of a Public Toilet.

The PCOs' found that toilets are often difficult to find, tucked away, out of sight. The

problem is not helped by poor signage and dark lighting (refer BSI 8300, Sections 12 and 14)

(BSI 2018). Signs are often too high up, too small or not clear. Steve's encounter (Picture 1)

left him feeling intimidated and disheartened:

[Insert Picture 1 here]:

Another challenge when looking for a toilet, was that there was none available. It was not

uncommon to discover a toilet that was locked or out of order with no indication about where

else to go.

> *There is a printed notice saying it was out of action or something like*
> *that... WHY was there no similar notice, telling people where the nearest*
> *Radar1 toilet was?* (James)

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[1] The National Key Scheme (NKS), previously referred to as RADAR keys, offer disabled people independent
access to locked public accessible toilets around the country. (Disability Information Scotland 2019)

Staff were infrequently on hand to help. When they were, the PCO experience was variable. This included encounters where the staff member did not know the whereabouts of the key to the accessible toilet, giving rise to lengthy delays before toilet access could be gained.

Change machines also produced concerns. Most of the machines encountered were positioned too high for a wheelchair user to reach. In some toilets, it was necessary to have the right coinage to enter a toilet. It can be a very complex task for someone with a cognitive impairment to decipher the instructions on these machines which are often in very small writing:

> *The first thing you come to is a machine that says CHANGE but it is hard*
> *to see what it costs so the Change machine is confusing. The multiple signs*
> *took some time to work out. This is a complex operation for any older*
> *person and impossible for many people with Alzheimer's. Felt confused*
> *and a bit of panic...* (Ian)

Theme 2: Ease of use

Public toilets can present a major challenge to use.

Disabled people often need a good amount of space in which to move around but the PCOs reported that many public toilet spaces, including 'accessible' toilets, were often too small to facilitate ease of movement, especially for wheelchair users. This may be due to the fact that many of the toilets included in this study met standards that were current when they were built but which are no longer compliant. There was rarely sufficient space for the use of large,

non-contact bins for continence pads. The problem is frequently exacerbated through clutter (some toilets are used as storage spaces), poor design and layout of equipment (Picture 2).

[Insert Picture 2 here]:

The PCOs highlighted additional factors that affected their capacity to use the toilet with comfort: sinks that are too small often splash water; equipment such as hand-driers, air fresheners and heaters often look similar, making it hard for anyone to work out which is which. Further, the positioning of these can make them problematic to use, e.g. hand-driers that are hard to reach. Buttons, without any accompanying label, compound this matter and it was not uncommon for the toilet user to be uncertain as to whether a door was locked or unlocked, again prompting anxiety. Moreover, the wide range of tap designs, particularly those that are activated by sensors, bring challenges about how to turn the water on and off, a key safety issue when water quickly becomes very hot.

[Insert Picture 3 here]:

Good lighting was emphasised as very important by many PCOS. At some sites, the cord or switch was hard to detect and took some time to locate, increasing the time and effort to achieve access.

> *I don't feel very comfortable here. Completely dark when you open door.*
> *Had to fumble for light switch Uncomfortable, floor filthy. Do not feel safe*
> *there. Dim – only emergency light working.* (Susan B)

Sometimes our PCOs found it difficult to work out how to switch the lights on, especially when they were triggered by a motion sensor. Entering into a room with non-functioning lights or those with a time delay between entering the toilet and being activated elicited feelings of anxiety and distress. Faintly lit rooms, or those with neon blue lights to deter drug use were described as disconcerting.

[Insert Picture 4 here]:

The treatment of emergency cords was a cause for major concern, signifying a, potentially major, health and safety issue. The red cords, designed to be easily accessible to pull in an emergency, were regularly seen to be wound-up, attached to bars or tucked away. The misplacement of an emergency cord can render it impossible to reach if, for example, a person was lying on the floor. This prospect prompted anxiety and dismay:

[Insert Picture 5 here]:

Theme 3: Emotional distress

Using public toilets can be distressing

Many of the sights, sounds, smells and physical encounters with toilets were upsetting to the PCOs, especially those with sensory impairments.

Sensory Impacts – Sight. Some of the PCOs experience visual challenges, and some with dementia have the additional challenge of perceptual problems. This means that they

misinterpret what they are seeing - for example, moving from darker to lighter flooring can be perceived as a step, increasing the risk of a fall. For the ageing eye and those with other visual challenges, contrast in tone is crucial if they are to see important features of a toilet – a white basin on a white wall and pale floor is for example, invisible. Other essential features such as the toilet roll holder also need to contrast with the wall if they are to be seen.

> *It is a good-sized, fully fitted (except shower) Changing Places toilet but the colour scheme is unremitting grey with very little contrast.* (Pat, and Susan W)

Too many colours, the use of bright colours and patterns, were also cited as the trigger for major distress, as was the alarming impact of some reflective surfaces and ill-judged mirror placement. Martin was completely startled when he sat on the toilet at one venue:

> *Hated mirror placement. The mirror was on the inside of door so that I saw myself whilst sitting on the toilet! Upsetting as I thought there was someone else in the room. Wallpaper very uncomfortable. It played havoc with my eyes. Confused* (Martin).

Sensory Impacts – Hearing. The challenging sensory experience of being exposed to the loud noises made by hand driers was another area raised by the PCOs. Many of these sounds are piercing to the ear and for those with hyperacusis, (when loud sounds are painful), they can be agonising:

> *The hand dryer is a huge problem for us. Millie hates the noise and will not enter when she sees one* (Emma).

Sensory Impacts – Smell. Toilets often smell unclean and lack hygiene. Additionally, there are problems linked to harsh, artificial smells, e.g. air fresheners. Although these are intended to reduce unpleasant smells, they can be overwhelming, disorientating and upsetting to the senses, especially when there is an unexpected release of spray from above.

Sensory Impacts – Emotional*.* The PCOs reported on a wide range of physical challenges but they also described how they *felt* when faced with difficulties. Many of the toilets were hard to find, unwelcoming, dirty and poorly maintained, sometimes with no staff in attendance to offer support. This resulted in feelings of distress and a sense of exclusion. The relationship between unpleasant physical experiences and emotional anguish was clearly evidenced, highlighting the acutely negative impacts of sensory overload. PCO discomfort and its ensuing distress was a principal theme. The adjectives in Box 1 reflect some of the felt responses expressed:

[Insert Box 1 here]:

A disregard of privacy in some toilet designs was noted. The PCOs gave more than one account of strangers walking into a Radar key accessed toilet. The Radar key toilet, (now National key scheme), is an independent system that provides access to over 10,000 locked toilets across the UK. It is designed to prevent vandalism and misuse and to provide entry solely to the people who really need these toilets. This can become problematic, however, if a member of staff is not on hand with the key at the time of need. A further issue is that, in some places, it is not apparent that the toilet is already in use (no vacant/engaged, or poorly depicted sign on the lock). As the key is universal, it opens all the locks, thus it is possible to open and walk in on someone already using the toilet. The PCOs found that some accessible

toilets are situated within a male or female toilet with no thought for the gender of the person who might be accompanying and supporting:

> *There's no standard way to indicate this (I've met it elsewhere) but the accessible toilet is a cubicle within an ordinary toilet. In this case the 'gents' consists of a urinal and wash-hand basin, then a door into one all-purpose toilet. This arrangement may cause embarrassment by someone seeing the wheelchair logo and going into the wrong unit. It can also be difficult when a disabled person is accompanied by a helper of the opposite sex.* (Mike)

The PCOs felt encouraged when toilets were well maintained and welcoming:

> *I was confident that the facility was clean to use. This was reassuring ... a really good example of a Changing Places toilet.* (Laura)

Unfortunately, such occurrences were the exception, rather than the norm and, even in the few examples of more recent toilet design and provision, including the CP toilets, the PCOs still identified a number of problems that might be encountered by different users. In the case above, a major airport, Laura also highlighted a lack of large signage outside the toilet (to facilitate the needs of those who are unable to look up at overhead signs), poor positioning of the soap dispenser for wheelchair users, and no user instructions for the hoist. Thus, some CP toilets, which are generally regarded as the Gold Standard in accessible toilet provision, still show areas for improvement. This points to the importance of involving a wide-ranging group of service users in the design and development of toilets to ensure that they meet the needs of prospective users.

Theme 5: Universal and unique needs

Needs identified mainly overlapped but there were some key differences

Universal needs

People with a variety of physical and cognitive impairments, and carers of people with profound and complex needs came together on this study to describe and document their experience of toilets when travelling. This revealed a hitherto unforeseen feature. It emerged that the process of being involved raised individual PCO awareness about the wider spectrum of issues beyond their own needs. They told us that it was rewarding to be involved with others and to learn about different needs, some of which are highly visible whilst others are invisible.

> *The advantage of doing surveys with a group is that everyone's got a slightly different outlook and experience. Finding out about the things that concern other people, that you need to take into account, I hadn't thought about before –things like sounds and smells, the noise of hand-driers.*
> (Mike)

Diverse Needs

Our data showed that, in the main, most people faced similar problems but a few specific needs were identified.

People with dementia are generally older so have many age-related impairments such as weaker muscles, poor eyesight and poor hearing. They also, but not uniquely, often have difficulties understanding how to use modern toilet equipment such as hands-free taps and press-button or automatic flush systems. Many experience sensory challenges that can alter perception and heighten sensitivity (Houston and Christie 2019). Mirrors and reflective

surfaces can be very alarming, as can the noise level of flushes and hand-driers. Patterned or speckled floors may look as if they have objects on them and can appear to be in motion. Poor colour contrasts were found to often result in an inability to differentiate the different aspects of a space and its contents.

People with PMLD also frequently experience similar sensory challenges. The parents of people with PMLD and wheelchair users may require a hoist, an adjustable bench with enough space next to it for a large wheelchair, and an adjustable sink and shower. Some carers related changing their relative on dirty toilet floors as there was no alternative.

[Insert Picture 6 here]:

Wheelchair users related that what is usually called 'an accessible toilet' with a low sink and a lower mirror need to be of an adequate size to be functional. In contrast to the problematic experience of mirrors described above, this piece of equipment is often vital to support the process of reversing in a wheelchair. Moreover, the toilet requires to be positioned with sufficient space on each side so that, depending on individual need, it is possible to pull themselves from their chair to the toilet from either side. From our data, it seems that this is rarely an option.

Recommendations for improvement

Based on their collective findings the PCOs put forward the following recommendations for improvement.

[Table 2 near here].

Discussion

In this article, we maintain that inaccessible toilets disregard Human Rights (HR) because they can severely limit citizens from taking part in everyday life. We found that using coproduction methods resulted in rich contextualised data that provided explicit evidence of everyday toilet use across a range of needs when travelling. The data are an authentic expression of the PCO findings, increasing their translational potential. Vitally, it boosts the voice of people with disabilities and their role as key stakeholders and agents of change in research that affects them. Another benefit, raised by PCOs, and reflected in other co-produced studies, .e.g. (Charlesworth 2018, Pernia and Salmón 2020), was the felt value of participating in something that held meaning, not only within their own lives, but those of others, too.

The importance of including the lay view is formally recognised through the Patient and Public Involvement (PPI) movement (Hayes, Buckland, and Tarpey 2014). Although emancipatory disability research is almost thirty years old, e.g., the participation of people with disabilities in research lags behind their able-bodied counterparts (Farmer and Macleod 2011, Rios et al. 2016). This is especially so for people with dementia and those with profound and complex physical and/or cognitive impairments (Savitch et al. 2006, Strnadová and Walmsley 2018, Thoft et al. 2018). There is, however, a growing understanding of the need to address this deficit to improve the quality and translational relevance of research outcomes (Ní Shé et al. 2019). Including people with dementia in research, for example, is increasingly viewed as critical to building dementia-friendly environments and ensuring the ongoing active participation of people with dementia in everyday life (Hebert and Scales

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2019). Our study adds to the growing body of context-based evidence that is creating a basis for future research in dementia, and other disability-friendly, initiatives (Hebert and Scales 2019, Savitch et al. 2006, Stevenson and Taylor 2019, Disability Research on Independent Living and Learning 2015, Hanson, Bichard, and Greed 2007).

Maintaining the values of the social model of disability within a Rights-based context is emphasised. Here, rights are perceived as entitlements to capabilities which necessarily have material and social prerequisites with Government intervention required to enable the latter (Nussbaum 2007). Rios et al. (2016) describe "accessibility" as a situation whereby a person's functional capacity and the functional demands of an environment are in harmony, allowing successful completion of an activity. The outcomes from our data analysis show that many public toilets on common travel routes and at destinations are not currently responsive to the needs of disabled people. Even toilets built to national standards and regulations do not always help with the everyday challenges faced by our group of co-researchers. This is surprising given that BSI committees generally include access experts and disabled people when reviewing standards concerned with access or where there is relevant content. Factors such as the age of the building and the date of refurbishment may offer some explanation as to why design issues are frequently unmet. Our findings echo earlier research outcomes featuring toilets as one of a range of barriers to accessing leisure outlets and demonstrate the need for ongoing evidence and campaigning work to bring about change (Innes, Page, and Cutler 2016, Help the Aged 2007, Hanson, Bichard, and Greed 2007).

Some disabilities, like dementia, are invisible and often overlooked. The result is a failure to adequately address specific needs and the repetition of difficult experiences (Houston and

Christie 2019). In our study, the PCOs clearly articulated such experiences through their expressed feelings of dismay, distress, anxiety and anger. Similar encounters and needs across the population (both able and disabled) are underlined in the work of Hanson, Bichard, and Greed (2007), and subsequently Slater and Jones (2018). People may resort to limiting activities outside of the home due to the feared consequences of being out in the community and faced with no, or inadequate, toilet facilities (Cole and Drennan 2019). The stigma and social isolation of not being able to engage in normal activities contravenes the citizenship right to dignity, empowerment, and autonomy (Clarke 2014, Slater and Jones 2018, The Royal Society for Public Health 2019, Taylor and Clayton-Turner 2017, Scottish Government 2018). Here, these issues were particularly emphasised by the parents of children and adults with PMLD but it is also the case for other groups. An example in point is the arts-based investigation undertaken by Slater and Jones (2018) which focused on the unmet needs and experiences of a variety of people including trans, queer, parents, mobile workers, and people with different religious beliefs.

We aimed to establish the top-shared priorities that service providers should focus on for designing accessible toilets for inclusive travel and participation. By bringing together people with a range of impairments, cognitive and physical, we sought to build a wider understanding of their needs and present a united voice on the major issues identified by them. A key feature that emerged from the data was the extent to which people with different forms of disability and carers shared similar experiences. It is apparent, however, that, despite substantial overlap in their experience and needs, there are a few unique toilet needs of people with particular disabilities that need to be addressed. The different needs linked to specific conditions can make it complicated for transport planners and providers to meet diverse, and sometimes conflicting, demands, as featured here, amongst other examples, in

relation to the use and placement of mirrors. Mirrors can be disturbing in toilets and other settings for someone with dementia who may not recognise the person in the mirror as themselves (Social Care Institute for Excellence 2015). In contrast, for the wheelchair user, mirrors can be an essential item of toilet equipment and their sensitive placement may be required to enable toilet use (BSI 2018, p.130). Different toilet designs are, therefore, a necessary part of the solution. Ramster, Greed, and Bichard (2018) warn, however, that changes to public toilet design and provision often proceed without expert guidance and an evidence-base to show the potentially positive or negative impacts on different user groups.

Additionally, the needs of people with PMLD are rarely considered. This is particularly important because, nowadays, more people with these needs live at home. On a positive note, considerable energy has been directed towards the issue of toilet design, access and provision through the CP toilet campaign (Grant 2013), and an increase in CP toilets which have all the facilities needed to change someone with PMLD (PAMIS 2017). Wheelchair users and other physically disabled people have, for some time, been involved in research to help with the development of standards and to bring about changes that make their world more accessible (Disability Rights UK 2020, BSI 2018). Confidence in going out is, however, linked to environmental predictors and feelings of self-efficacy (Sakakibara et al. 2014). Neuro-diverse people, including people with dementia, whose needs usually combine those of older people with both cognitive and sensory impairments, have only recently been considered 'disabled'. The recognition of dementia as a disability carries major implications for the future design and delivery of supports and services (Milton 2015). As yet though, no distinct campaigning voice is raising awareness about their specific needs for enabling design features in toilets. Changes to Standards accord some recognition to cognitive and sensory problems but these do not go far enough (BSI 2018). Our findings reflect the sentiments expressed by Bichard,

Hanson, and Greed (2006) who impress the critical importance of hearing the experiences of people who are disabled in different ways to ensure that the range of needs is taken into consideration. Bringing together people with different disabilities can create cross-fertile ground for sharing knowledge and, as shown here, boosts the potential to generate greater momentum for all-inclusive change.

The disabled people's movement developed emancipatory research methods based on HR principles (Beresford 2007). These are integral to the Charter for Rights of People with Disabilities which offers an explanatory platform for the fulfilment of existing universal HR in the disability context (Cahill 2018, p.48). It positions disabled persons as right holders and posits that impairment may not be used as a justification for denial or restrictions of HR (Degener 2016). This requires a more focused attention on dismantling the structural barriers that prevent people from exercising their individual citizenship freedoms within a democratic society. We consider that the alignment of the social model of disability to the legislative framework of HR can offer a powerful channel to advance and enable the capacity for self-determination and the needs of all members of society.

People with dementia can, and are, as shown here, starting to take on the role of activist. The rights-based, relational model opens up an important avenue to address existing barriers that prevent full participation in society (Shakespeare, Zeilig, and Mittler 2019). The European Disability Strategy, rooted in the CRPD, aims to 'eliminate barriers to access facing people with disabilities' to enable full and independent living and be included in 'all aspects of social and economic life' .

To fulfil these objectives for all, community services and facilities for the general population need to be available on an equal basis to persons with disabilities and be responsive to their needs (UN General Assembly 2006). In respect of toilets whilst travelling, despite some positive advances, the reality is some way off. We prioritise two issues for urgent attention: 1) the full implementation of standards for toilet design as laid out by the BSI Code of Practice for the "Design of an accessible and inclusive built environment" (BSI 2018) as these are, in the main, not being met; 2) the BSI Standards require to be reviewed and endorsed by people who represent the full range of access needs. The findings from this modest study provided context-based evidence collected by a range of disabled people and carers. Our hope is that this will strengthen ongoing debates around toilet provision and support the potential for a profound change in the future planning and delivery of toilet provision.

Limitations

A Public Inconvenience was a small project with limited funds and time inputs from the research coordinator, which reduced the overall scale of the investigation. Regardless, the PCOs gathered important data from nine regions across Scotland, demonstrating the universal nature of issues raised. Although our PCOs represented a range of disabilities, this was by no means exhaustive and the needs of, for example, blind and partially sighted people, were not included pointing to the need for additional studies to address the full scope of needs.

The emphasis was on toilets linked to transport and travel hubs but some of our PCOs undertook visits to a wider range of premises, capturing places of particular importance to them. This extended the project focus, and points to one of the challenges of maintaining

research boundaries within the context of a coproduction design. It also, however, highlights the advantage of increased relevance in respect of the PCO needs and how their unique contribution supports not only researcher self-reflection but also reflection on the role and position of academic frameworks (Woelders et al. 2015).

Conclusion

This study has revealed that, despite growing awareness about the difficulties experienced by people with dementia and other cognitive and physical impairments with accessing toilets, there is still much to be done. Although most needs are universal in nature, there are some specific needs that require particular attention. Our findings demonstrate a pressing need for toilet planners, designers and providers to adhere to existing standards and regulations for toilet design. Further, it is imperative that people with different cognitive and physical impairments are adequately represented in future revisions to toilet specifications and in the planning of their provision. Following the ethos of a Human Rights-based design, the co-researcher contributions to the project have been critical to its success. Although the literature on toilet provision is expanding further exploration on a larger scale is needed to ensure that the needs of all people are addressed. The voices of people with disabilities are gradually being listened to but are not yet fully heard, particularly within the context of dementia friendly initiatives, where toilet champions are in short supply. Accurate and relevant evidence can then inform public policy at local, national and international levels.

Declaration of Conflicting Interests

The Author(s) declare(s) that there is no conflict of interest.

Data availability statement

The data set associated with this paper can be accessed via the UK Data Service, ReShare].

repository at https://reshare.ukdataservice.ac.uk/854233/, reference number [854233].

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Table 1. Recruitment of Participant Co-researchers – Inclusion criteria

Attributes	Criterion	Rationale
Age	≥18 years	Inclusion of children as PCOs not part of the study design but could participate alongside parents
Gender	Any	No discrimination
Living with Dementia, Disabled or carer	Diagnosis of dementia or another cognitive and/or physical impairment, or family carer of a	The research aim was to investigate the specific needs of people with dementia and/or other impairments

	child or adult with profound and complex needs	
Written and/or verbal aptitudes	Able to communicate personal experience (with support if needed)	Ability to give personal consent to take part and express experience of toilet provisions
Other aptitudes	Able to: Travel and use a smart phone or camera (with support if needed)	Key focus for data collection was to document, through photographs and diaries, the use and experience of toilet facilities while travelling

Table 2: Photo diary template

Name: Location: Date:	
WHAT DO YOU NOTICE?	**HOW DOES IT MAKE YOU FEEL?** (for example: uncomfortable? safe? anxious?)
Finding the toilet - are they easy to find? what do you notice about the signage?	
What do you **see**? (how is the lighting? are surfaces or reflections unhelpful?)	
What do you **hear**? (are there loud noises? confusing noises?)	
What do you **smell**? (does the environment smell pleasant? are there artificial scents?)	
How **easy** is it to use? (operating taps, opening doors, locking and unlocking…)	
How **helpful** are people?	
Anything else that you notice…	

Table 3. Themes and sub-themes

Themes	Sub-themes
Difficulties with accessing the toilet	Access; Signs and symbols; Change machines
Ease of use	Lay-out; Design, e.g. Confusing buttons; Colour contrast; Lighting and reflections; Emergency cords;
Emotional Distress	Sensory impacts, e.g. noise, smell often led to feelings of anxiety, confusion etc.
Universal and unique needs	Similar needs; Diverse needs

Table 4. PCO recommendations for improving toilets when out and about travelling

Access
- Governments should ensure that transport providers
- improve the standard of public toilet facilities in transport hubs, and on vehicles, such as buses, ferries and trains
- Public toilets need to be really visible and easy to get to with clear signage and directions that take you straight to the toilet
- Policy makers and planners need to make certain that
- public toilets are situated in places that provide universal easy access
- Businesses and Local Authorities should provide clear and detailed information about their toilets to help people to plan journeys
- Transport providers and other businesses should provide staff training to ensure that everyone understands their role and responsibilities

Ease of use
- Those who create and regulate standards could insist that toilet planners, designers and providers closely adhere to existing regulations and guidance to avoid the problems highlighted here
- Regular maintenance of equipment is essential
- Mystery shopping in public toilets by prospective users to assess ease of use and satisfaction levels

Distress
- Policy makers and the general public need to be made aware of the distress caused by poor design and equipment.
- Greater care and attention needs to be given to toilet design, reflecting its key importance and demonstrating sensitivity to the needs and feelings of different users, e.g. improving on the current emergency cord
- Service providers and authorities can provide sufficient staff to ensure the maintenance and hygiene of public toilets

Universal and unique needs	• People with a range of cognitive and physical impairments and carers need to be involved in designing toilets, writing and checking standards, and developing guidelines and training courses

Box 1: PCO sensory responses to toilets encountered during data collection

> *"intimidating"*
> *"anxious"*
> *"disorientated"*
> *"awful"*
> *"confused";*
> *"a bit of panic"*
> *"disgusted"*
> *"complicated"*
> *"uncomfortable"*
> *"gloomy"*
> *"a bit frightening"*
> *"quite cold"*
> *"nauseous"*
> *"off-putting"*
> *"overlooked"*

Captions for Figures

Picture 1. Steve (Access) – 'Very difficult to locate. No signage at all in the front of the main shopping areas to indicate disabled facilities. I took over 15 minutes to eventually locate toilets in an outhouse area behind the centre, along a narrow, dirty and poorly lit alley-way. Toilets in outhouse behind the alley way. Toilets seemed very threatening with large iron bars (like a jail block). Poor first experience.'

Picture 2. Mike – 'Looks like something knocked up by a very amateur handyman using whatever bits and pieces were to hand. No cohesion in the design. Narrowish, so difficult to turn to lock the door. No red cord, but a bell-push completely out of reach from a chair, or anybody sitting on the toilet. It's doubtful if anyone sitting on the toilet can reach the toilet paper. The wash-hand basin has an upstanding board at the front, and a wheelchair user can't even reach the basin, let alone the taps or the soap. There is a huge mirror – good for those of six foot six or more! This is a disgrace. For a station the size and status of Waverley[2] this should be discounted – leaving it with only one accessible toilet (which is itself only just adequate).'

Picture 3. Emma – 'Poor design consideration taking away the independence of people. Opting for style over function.'

Picture 4. Laura – 'The lighting was really poor and like nothing I have seen. As you entered it was dimly lit and then above the toilets were blue lights, which was really dark and confusing.'

Picture 5. James – 'To my horror, the red emergency cord was tied into a big round knot. I did not sit on the toilet but crouched down and I could not reach the cord. Do these cords get "put up" for floor cleaning purposes, then someone forgets to let them back down again???'

Picture 6. Pat and Susan - "This is a good sized, well-appointed Changing Places toilet with everything you would hope for including a shower. The toilet was light, bright and clean. It has a bed, hoist, moveable sink, several bins, mirror at an appropriate height**."**

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[2] Main train station in the capital city of Edinburgh