

The Challenges of Hearing Disability and Age-Informed Citizen Science During COVID-19

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Abstract

The World Health Organization estimates that by 2040, one in every ten people will experience a hearing disability (World Health Organization, n.d.). In 2017, 3.6% of working adults and 12.2% of older adults in Canada had a form of hearing disability (Morris, 2017). Older adults are notably affected as hearing disabilities increase with age (Morris, 2017). The built environment creates barriers for those with hearing disabilities, especially in older adults (Kochtitzky, 2011). There is a lack of research examining the effects of the built environment on people with hearing disabilities (Davies et al., 2001; Prescott et al., 2020). Current research tools focus on objective, quantifiable measures of the built environment rather than the subjective perspectives of disability populations who use the built environment (Kan et al., 2020). Researchers often lack disability-specific knowledge when collaborating with disability populations (Kelly-Corless, 2020; McKee et al., 2012; Singleton et al., 2014). The COVID-19 pandemic exacerbated existing environmental barriers for people with hearing disabilities and influenced the process of collaborative research (Tremblay et al., 2021). Future research on people with hearing disabilities and the built environment requires researchers to collaborate with the population of concern to ensure future changes are tailored to their needs.

Keywords: hearing disability, built environment, research tools, accessibility

Background

As the Canadian population rapidly ages, a growing number of people are aging with and into disabilities (World Health Organization, n.d.; Statistics Canada, n.d.). Nearly a quarter of the population aged 15 or older have one or more disabilities (Morris, 2017). Approximately 18.5% of Canada's population is 65 and older (older adults) (Statistics Canada, n.d.). The prevalence of disabilities increases with age; older adults are more likely to experience disabilities than younger adults (Morris, 2017). In 2017, 3.6% of working adults and 12.2% of older adults in Canada had a hearing disability (Morris, 2017). Genetic or acquired hearing disabilities include but are not limited to conductive, sensorineural, mixed hearing loss, and auditory neuropathy spectrum disorder (CDC, 2021; Isaacson & Vora, 2003). Hearing disabilities can result from sound blockages (conductive) and nerve pathway damage (Sensorineural and Auditory Neuropathy Spectrum Disorder). A mix of conductive and sensorineural hearing loss can also occur (CDC, 2021; Isaacson & Vora, 2003). Presbycusis, the deterioration of hearing in older adults, is a form of bilateral sensorineural hearing loss (Isaacson & Vora, 2003). Globally, by 2050, one in ten people will experience hearing loss (World Health Organization, n.d.; Statistics Canada, n.d.). Despite this projection, there is a lack of consideration for establishing user-led research and tools involving the built environment and the input of people with disabilities, especially those with hearing disabilities (World Health Organization, n.d.; Hersh et al., 2010).

The biomedical paradigm is a dominant perspective that suggests disability is a sickness that requires medical or technological treatments (Rioux, 1997). The perspective views disability as a problem that needs “fixing” by professionals and the popularity of this model in the early 20th century increased the tendency for people with disabilities to conform to unsupportive environments (Rioux, 1997). Modernist planning movements in the early-mid 20th century also

aligned closely with this biomedical perspective (Fainstein, n.d.). Planners were the technicians who identified and "fixed" urban environmental issues that they saw as problematic, akin to how medicine could "fix" those with disabilities (Fainstein, n.d.). However, urban planning often overlooked people with disabilities, older adults, and other vulnerable, underrepresented populations (Fainstein, n.d.). When it came to fixing urban environmental issues, planners often held abled perspectives, resulting in changes that did not accommodate people with disabilities (Fainstein, n.d.). Under this paradigm, individuals with disabilities unjustly bear responsibility for the environmental limitations created by society and city design.

Models like the disability creation process model (DCP) contrast the biomedical paradigm (Fougeyrollas et al., 2019). DCP frames disability as an external phenomenon and places the responsibility of creating accommodating environments on society rather than on individuals with disabilities. The model situates disability as an outcome of unsupportive environments, including the urban environment, rather than individual physical conditions (Fougeyrollas et al., 2019). It implies that the physical environment impacts an individual's capability, shifting their ability to disability. Whether the environment acts as a barrier or facilitator, it determines the extent of disability an individual experiences (Fougeyrollas et al., 2019). Therefore, disabling situations under this model occur when individuals encounter environmental barriers that hinder their daily lives (Fougeyrollas et al., 2019).

In the context of COVID-19, disabling situations have presented themselves as by-products of world views that do not consider the perspectives of individuals with disabilities. With urban environments already creating barriers, the addition of COVID-19 safety measures further complicated how individuals could function and navigate within their communities. For example, outdoor patios and street furniture implemented to encourage social distancing

overlooked the needs of people with disabilities. For those who communicate using sign language, patio and street furniture can contribute to sidewalk distractions and limit the area where people can comfortably use sign language (Paling, 2021; Mahmood et al., 2021). These obstacles contribute to traffic safety concerns since insufficient space for sign language may encourage pedestrians to enter traffic lanes to maneuver around obstacles (Paling, 2021). Additionally, street patio patrons add to the number of auditory distractions individuals with hearing disabilities must be aware of when navigating the sidewalk. This may become overwhelming or lead to an inattentive and distracted crossing at intersections (Paling, 2021). These concerns exemplify the extent that small-scale environmental changes can have on individuals with disabilities.

Inaction at the micro-level may have large-scale repercussions if there are no efforts to facilitate supportive physical environments. As disability prevalence increases with age, not only are those with current hearing disabilities impacted, but current non-disabled older adults aging into future hearing disabilities will also be affected (Bizier et al., 2016; Morris, 2017). Examining the impact of the built environment on people with hearing disabilities can help stakeholders and decision-makers better understand and mediate their needs. Combining a citizen science approach and principles of the DCP model in research provides knowledge of best practices and a more nuanced perspective toward the effects of the built environment.

The Built Environment

The built environment refers to human-made components of the environment where society functions (Gorse et al., 2013). These everyday features encompass many urban cities such as sidewalks, crosswalks, traffic signals, and street furniture such as benches and plants (Gorse et al., 2013). These features may function as barriers for those with hearing disabilities.

For example, pedestrian signals with inadequate visual indicators impact safety at crosswalks. Individuals with hearing disabilities may not hear auditory indicators and rely solely on visual indicators to know when and how much time is left to cross (Kochtitzky, 2011). Additionally, stairs, rather than ramps, could be tripping hazards for those engaged in vision-centric modes of communication, such as sign language (Ground UP Issue 07, 2018). These features may be perceived as facilitators to nondisabled users, but people with disabilities may experience them as barriers.

Hearing disabilities have been overlooked in environmental accessibility because they appear ‘invisible’ and are less affected by design choices than other disabilities, such as mobility or vision impairments (Hersh et al., 2010). Hearing disabilities, however, can influence how individuals participate and communicate within society, such as non-participation in Deaf culture, age-based factors of hearing loss, hearing device use, and sign language use (“Communicating With Deaf Individuals,” n.d.). Older adults with hearing disabilities may face compounded effects of the city design that do not accommodate their various needs.

The built environment plays a significant role in mobility and how one navigates their communities, but its effects notably impact older adults (Kerr et al., n.d.; Levasseur et al., 2015). As older adults age, their physical travel distance reduces, including travel within their built environments such as homes, neighbourhoods, and communities (Kerr et al., n.d.; Levasseur et al., 2015). Features of the built environment that were not previously barriers may become barriers as individuals age (Kan et al., 2020). Age-related hearing loss can, therefore, lead to a decrease in mobility (Polku et al., 2018).

The immediate physical environment by older adults' homes is crucial to their lives (Chaudhury et al., 2016). Poorly designed and maintained environments can lead to physical and

mental health concerns (Chaudhury et al., 2016). For example, cracked sidewalks or poor lighting can discourage the use of the built environment, leading to increased social isolation and physical health concerns (Chaudhury et al., 2016; Kerr et al., n.d.). External environmental influences may be critical factors in determining how well individuals age with a disability, including their ability to sustain social engagement and participation (Mahmood & Keating, 2012). When supportive features are not present, individuals aging with and into hearing disability may be less likely to engage in the community or participate in the physical activity they need, leading to physical and mental health concerns (Kerr et al., n.d.; Polku et al., 2018).

Data Collection

Hearing Disabilities Populations

In addition to the current literature gap on the built environmental barriers for those with hearing disabilities, there is a gap in conducting research with people with disabilities (Kelly-Corless, 2020; Singleton et al., 2014). Little is known regarding the best research practices for collaboration with people with hearing disabilities, especially outside technology and educational contexts (Kelly-Corless, 2020; McKee et al., 2012; Singleton et al., 2014). However, a growing body of non-empirical research in research etiquette, ethics, and inclusivity provides insight into communication with respective groups of people with disabilities (National Association of Deaf, 2020). The present gap in research practice literature can be partly attributed to difficulties in producing research findings—namely researcher-participant language barriers, sensitivity training standards, and participant-accessible research materials (Kelly-Corless, 2020; McKee et al., 2012; Singleton et al., 2014).

Many Deaf/hard-of-hearing people communicate using sign language, resulting in potential researcher-participant communication barriers and research translation errors (Jones et

al., 2006; Quer & Steinbach, 2019). Variables including participant language acquisition, bilingual signers, native and non-native signers, varying sign languages, geographical variation, and other individual and social factors affect data collection and interpreter translation (Jones et al., 2006; Quer & Steinbach, 2019). The researcher's questions may also not be translated correctly when shared with participants (Jones et al., 2006).

Language barriers can affect how well participants understand information presented by researchers, especially during data collection. Two conditions are essential to reducing mistrust, anxiety, and confusion between researchers and participants during the consent process of a study: researcher fluency in region-specific sign language and familiarity with Deaf culture (McKee et al., 2013). Research teams need more careful preparative work and relevant sensitivity training. A researcher's lack of hearing disability-specific knowledge may cause Deaf or hard-of-hearing research participants to feel worried or uncomfortable (Singleton et al., 2014). Similarly, different levels of language proficiency should be accommodated in surveys or tool development involving sign language (Eckhardt & Anastas, 2007). For example, accessible, informed research materials should be provided in a visual rather than auditory format.

The research team's ability to manage a language barrier significantly affects the study's findings as well as the participants' feelings and perceptions. User-led research should be standard in this area; involving people with disabilities, who are the most affected, increases the data's applicability outside of the research (Rios et al., 2016).

COVID-19

During the onset of the pandemic, only primary clinical research could proceed in British Columbia (Government of British Columbia, 2020). Technology or virtual means of data collection were substitutes for in-person research during these times. However, audit tools

required for in-person methods for data collection were not replaced. Concerns exist regarding the standard of in-person research maintained throughout the pandemic, as technology and health directive safety procedures can subtly influence participant data collection processes (Tremblay et al., 2021). Adherence to research criteria is often utilized to oversee high-quality research. However, it can be challenging to meet these standards when trustworthiness, rapport, reflexivity, and other key research areas are more challenging to build during health precautionary research collection (Tremblay et al., 2021). For example, active researcher reflection and field-time interaction are crucial in building participant-researcher trust and rapport. Time sensitivity and physical distancing during the pandemic may deter traditional qualitative methods as researchers are concerned with collecting results faster to reduce the spread of COVID-19 (Tremblay et al., 2021). These scenarios may result in heightened participant stress as a side effect of perceived researcher mistrust or doubt due to a lack of rapport and trust building. Methodological rigour is also questioned as the depth and exploration of questions can be complex in altered in-person settings where probing, nonverbal cues, and context-based data are hard to notice through a distanced and masked meeting (Tremblay et al., 2021). Considerations of methodological rigour, accessibility, participant stressors, and disability-informed practices are essential for future research practices.

As research returns to in-person methods, attention must be continually placed on accessibility and disability-informed practices as people with disabilities may have overlooked needs. For example, those with hearing disabilities may find high participation in video conferences taxing (McNamara & Stanch, 2021). Feelings of fatigue resulting from a need to increase concentration to listen and lipread are pertinent even without the present influences of the pandemic (Punch, 2016). These adverse effects are exacerbated if accommodations such as

an interpreter or accurate real-time transcription are unavailable. Accessible communication is a mutual process that involves providing information over various in-person or remote formats depending on what is most comfortable for those involved (Accessibility Standards Canada, n.d.). Accessibility formats, language flexibility, and culturally appropriate language, among other essential practice formats, need to be maintained in the context of the pandemic to prevent exacerbation of these already existent stressors among people who are Deaf (Accessibility Standards Canada, n.d.; About Accessible Communication Services - Wavefront Centre for Communication Accessibility, n.d.).

Those engaged in research projects may be concurrently affected by mental health or other pandemic aggravations ranging from financial to physical detriment (Cardel et al., 2020). In 2020, pandemic-related anxiety and depression were found to lead to waning motivation to follow behavioural or intervention protocols (Cardel et al., 2020). This finding suggests that COVID-19-related mental health stress potentially influences research results (Cardel et al., 2020). Persons with disability and other vulnerable groups can face further exacerbated mental health outcomes due to pandemic stressors and elevated social isolation (Ciciurkaite et al., 2022). Furthermore, the rapid return to in-person means of research has the potential to both improve or inflame stress. Without support, those with hearing disabilities may face increased strain throughout these adaptive research processes (McNamara & Stanch, 2021).

In-person accommodation will be crucial for hearing disabilities. Individuals who are Deaf or hard of hearing may have their communication partner utilize alternative protective measures other than face masks (Accessibility Standards Canada, n.d.). A long clear face shield that reaches past the chin would be the most appropriate alternative for visualizing the mouth and facial expressions of communication partners (Accessibility Standards Canada, n.d.). Other

crucial hearing accommodations can be implemented such as, note-takers, sign language interpreters, captioning of all material, appropriate acoustic conditions, and circulation of transcripts (McNamara & Stanch, 2021). Moving forward, more consideration towards tailored accessibility and disability-informed practices will be crucial in research to negate exacerbating current built environments or creating built environments that lead to disabling situations.

User-led Tools for Evaluating the Neighbourhood Built Environment

People with disabilities have been under-represented in health research. This raises the question of whether changes based on established research accurately represent the general population (Rios et al., 2016). Excluding people with disabilities in research omits the input of a population subset that can be heavily impacted by decision-making and policy changes. User-led tools, however, can address the exclusion of people with disabilities in research (Rios et al., 2016). User-led tools allow for direct communication between researchers and people with disabilities, offering an opportunity to hear the nuances of the built environment (Pineo et al., 2020; Rios et al., 2016). As a result, research involving people with disabilities can inform decision-making regarding changing the built environment (Rios et al., 2016). Involving citizens in the research process also provides an opportunity to see how they can lead to changes in their communities (Rios et al., 2016). Citizens become citizen scientists by collaborating directly with researchers in community-based participatory research (Vaughn & Jacquez, 2020). Citizen scientists can provide input from developing assessment tools (e.g., user-led tools) to collecting data and engaging with community stakeholders (Vaughn & Jacquez, 2020). Researchers cannot speak on experiences they have not lived (Rios et al., 2016). Citizens who live their daily lives in these environments can voice the impacts of their neighbourhoods on their mental and physical health.

The involvement of people with disabilities is limited in research, as existing recruitment criteria and tools may not accommodate their participation (Meyers & Andresen, 2000).

Researchers often utilize existing environmental audit tools to assess the role of aging and the built environment in areas such as safety, accessibility, and social life (Kan et al., 2020). With a focus on objective measures and findings, researcher-led tools are typically prioritized over the perspectives of community members with lived experience. User-led tools address this limitation by including the target population in developing and using the tool, thus integrating the lived experience of those most impacted by research outcomes (Mahmood et al., 2020).

User-led tools hold many advantages not captured by researcher-led tools (Jelks et al., 2018; Kan et al., 2020). The data collected from a user-led tool called Urban Health indicates that complicated phenomena can be communicated to non-residents using the data residents collect (Pineo et al., 2020). The residents provide a more nuanced understanding of the environmental barriers experienced, thus facilitating the solution process (Pineo et al., 2020). Through participation in the research process, residents can address concerns that would otherwise go unheard (Pineo et al., 2020). User-led tools enable the active participation of people with lived experience, empowering them to get involved in the research process and inform more targeted community change (Mahmood et al., 2020). With the emergence of research increasingly involving people with lived experiences, the doors to more applicable research contributed by those impacted the most will begin to open.

The literature acknowledges that people with disabilities experience numerous environmental barriers in their daily lives. However, there is a lack of literature highlighting this relationship in those who are Deaf or hard of hearing (Davies et al., 2001; Prescott et al., 2020). Complexities arise when trying to improve accessibility within the research process, such as a

lack of disability-specific knowledge from researchers (Kelly-Corless, 2020). Insufficient knowledge marginalizes people with hearing disabilities in research (Anderson et al., 2023). Researchers may not undergo sensitivity training or consider the needs of hearing disability populations in data collection planning. They may exclude financial budgeting for sign language interpreters or, in the context of COVID-19, may need to be made aware of additional mental and physical tolls from collecting data (Cardel et al., 2020; McNamara & Stanch, 2021). Without sensitivity training, researchers may inadvertently create potential mistrust with the participant due to discrimination (Anderson et al., 2023). The lack of disability-specific knowledge can result in the loss of critical user perspectives (Anderson et al., 2023). Research may also lose the perspective of those aging into hearing disabilities, as many aging adults do not define themselves as having a disability (Lin et al., 2019). Hearing loss falls on a spectrum; therefore, many older adults may perceive this loss as a part of the normal aging process and may be overlooked (Lin et al., 2019). Connecting with participants during the research process is essential to producing tools to address the nuances of disabling barriers while facilitating valid and applicable findings.

There is a need to develop assessment tools for the built environment tailored toward the experiences of people with hearing disabilities (Prescott et al., 2020). Environmental audit tools assess aspects of the built environment created for various uses (Kan et al., 2020). When used by people with disabilities, these tools would assist in bridging the knowledge gap: a means of better understanding aspects in the built environment that may inadvertently provoke disabling situations.

Implications for Future Research

Research must move towards creating and employing user-led tools that assess the built environment. With the rapidly aging population, the walkability of neighbourhoods and communities for older adults becomes increasingly important given the onset of the risk of disability (Kerr et al., n.d.; Chaudhury et al., 2011). One of the current efforts to address this is through the Mobility, Access, and Participation (MAP) project, a collaboration funded by the Social Sciences and Humanities Research Council and conducted between Simon Fraser University, the University of British Columbia, and the University of Laval with various municipalities, non-profits, and partners.

The MAP project aims to work within communities to bring Canada closer to its goal of becoming barrier-free by 2040, as proposed by the 2019 Accessible Canada Act (ACA) (Government of Canada, 2023). The ACA aims to identify and remove barriers in the built environment for all people and prioritizes supporting diverse types of communication, including sign language (Government of Canada, 2023). In alignment with ACA, the MAP project is currently developing a user-led environmental audit tool, the Stakeholders Walkability/Wheelability Audit in Neighbourhoods (SWAN) tool, for people who are hard of hearing or Deaf. By employing community-based participatory research, this tool will work directly with people with lived experience to determine what built environment features are barriers or facilitators to their out-of-home mobility and participation.

The SWAN tool effectively integrates people's perspectives with lived experience, leading to community-level environmental change (Mahmood et al., 2020). While the current tool does not encapsulate the experiences of people with hearing disabilities, it can support other disability populations (Mahmood et al., 2020; Gan et al., 2022). As a seminal user-led tool focused on disability, it exemplifies how citizens with disabilities can empower themselves

through participatory research (Mahmood et al., 2020). To ensure the tool applies to those with hearing disabilities, researchers from SWAN collaborate with people with hearing disabilities. The hearing tool questions focus on clarity and the effects of environmental noise, as these aspects can influence the accessibility of people with hearing disabilities. Although hearing exists on a spectrum and these modifications do not encompass the concerns of all individuals with hearing disabilities, approaching research this way may provide insight into the considerations researchers should adopt. Nevertheless, more should be done beyond this project to address the current state of research involving people with disabilities. When creating and modifying physical and social environments, policymakers and stakeholders must consider the perspectives of people with lived experience.

Conclusion

Barriers developed through the influence of biomedical models and non-inclusive urban design exacerbate disabilities. Stakeholders and decision-makers need to address these barriers. The onus should not be on those with hearing disabilities to overcome environmental barriers created through exclusionary and inadequate urban planning (Fougeyrollas et al., 2019). Improving the current design of the built environment should involve people with disabilities in decision-making and research. Hence, collaboration between citizens, stakeholders, policymakers, and communities is necessary to overcome the challenges of conducting user-led research with hearing disability populations, especially during unexpected changes such as the COVID-19 pandemic. A lack of opportunities for hearing disability populations, accessibility issues, and the knowledge of specific environmental contexts need to be clarified and resolved through citizen science research. In other words, a better-designed future can be achieved by

conducting research with a community-based participatory approach and applying knowledge of best practices when collaborating with people with disabilities.

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