

ATTITUDINAL BARRIERS FACED BY YOUNG ADULTS WITH DISABILITIES AS DEPICTED THROUGH PHOTOVOICE

Jacque Ripat, Roberta L. Woodgate
University of Manitoba

INTRODUCTION

In Canada, 3.8 million Canadians (13.7%) report living with a disability, with 4.4% of individuals aged 15-24 and 6.5% of those aged 25-44 self-identifying a disability (Statistics Canada, 2012). While some acquired their disability in adulthood, many were born with a disability or acquired it in childhood. These young adults have experienced growing up with a disability as engaged and contributing members of their families and communities (Stewart, 2006). Young people with disabilities have the same wishes and aspirations as their peers (Skar, 2003) resulting in a need to explore ways that young adults with disabilities are able to fully participate in all desired aspects of their lives.

While Canadian statistics specific to young adults are not readily available, 81.3% of Canadians with disabilities report using one or more assistive technology (AT; Statistics Canada, 2012), resulting in a need to examine the experiences of AT users. The intersection of the environment (physical, social, structural, institutional, and attitudinal) and the AT used by an individual can create a situation that promotes, or alternatively creates barriers to, participation. There have been recent advances in the development of accessibility legislation in Canada, and a resultant increasing awareness of the importance of creating accessible public spaces. The social environment, including family supports, has often been identified as a facilitator of AT use rather than a barrier (Ripat & Woodgate, 2012). However, recent research has indicated that negative community and societal attitudes continue to emerge as a primary barrier to participation for adults (Hammel et al., 2015; Lindsay, 2015) and for children and youth with disabilities (Anaby et al., 2013). Clearly attitudinal barriers towards

people with disabilities remains an unaddressed issue.

AIM

The overall aim of this qualitative inquiry (Charmaz, 2006) was to gain an understanding of the individual, physical, social, cultural, attitudinal, and institutional environmental conditions that contribute to how young adults with disabilities who use AT devices participate in daily life. The focus of the current paper is to share findings related to the attitudinal environment.

METHODS

Twenty young adults (ages 18-35) who had used AT (e.g., wheelchairs, communication devices, prosthetics) since childhood or adolescence were recruited to participate in this study. Data were collected using a combination of individual interviews, photovoice, and focus groups. Photovoice is a participatory data collection method, focused on social change and action, where individuals are provided with cameras, and asked to take pictures of places, events, or images that represent meaningful experiences to them (Wang & Burris, 1997). In this study, participants engaged in an initial individual interview, received digital cameras (with custom adaptations to ensure participants were able to independently take photos, for example with switch adaptations or mounting devices), and asked to take pictures that represented their community participation experiences. Participants then engaged in a second interview to select and caption 12-15 of their photos. Finally, participants attended a focus group to collectively discuss their photos and experiences. Data were transcribed verbatim, and analyzed using an inductive thematic analysis approach (Braun & Clarke, 2006). Rigour was maintained by engaging with

participants on multiple occasions and over a prolonged data collection period, upholding the fidelity of the participant's voices through use of direct quotes and photos, confirming findings in the focus group, and maintaining an audit trail describing research processes and decisions.

RESULTS

Four primary themes emerged that related to the attitudinal aspects of the environment: 1. Seen and treated as different; 2. Assumptions made; 3. Impatience; 4. Photos as a means of consciousness-raising. While the first three themes emerged primarily through analysis of the individual participant photos/interviews, the fourth theme emerged through the interaction between participants in the focus group discussion.

Seen and treated as different

Participants described how use of their AT became a visible sign of their disability, and how this resulted in being treated in a different way that others perceived as special. For example, one young man took a picture of his portable word processor and shared: *"I know ever since I've had the AlphaSmart, whenever I use it on like tests, people are always like 'oh why do you get to use a keyboard and we don't?'. Like, because I'm sure everyone, like everyone in my generation can probably type faster than they write, but I mean they can also all write at a decent speed so, there's always a bit of that reaction like, well you get something we don't".*

Many participants discussed how their AT created isolating situations, where they were left out of activities due to an environment's physical inaccessibility or incompatibility with their AT, or where they felt isolated due to others' discomfort with their use of AT. For example, one young adult described: *"So I would rather say that using assistive technology put me in a situation where the people would leave me alone."*

Assumptions made

Participants dealt with general assumptions that were made about them by others. For example, a young man who used a prosthetic

leg shared: *"Some people just automatically assume that well you're not gonna be able to do it...maybe I'm not as fast as the next guy, but somebody with two legs might not be as fast as the next guy, right?"* At times, the assumptions made were based on ignorance, as depicted by one young woman who used a power wheelchair. She described her photo as follows: *"My neighbours like to park right in front of my ramp...usually right in front of our driveway. I've actually fallen out of my wheelchair trying to get around them...they just refuse to park elsewhere...even though they've been towed, they've gotten tickets".*

Impatience

Participants reported how others did not take the time to allow them to speak, or were intolerant of their need for extra time to engage in activities. One participant who used a speech generating device took a photo of a laminated list that she created and captioned it: *"Communication guidelines sign posted in my apartment; not everyone takes the time to read it".* Another participant who used a power wheelchair took a photo of a bus with the ramp lowered, and captioned the photo: *"Fully capable of driving on the bus and driving off it, but there's no time. You know, the driver's got to go..."*

Photos as a means of consciousness-raising

Through the focus group discussions, it was evident that young adults were able to consider the value of photos as a way of raising their own individual consciousness and as a platform for identifying suggestions on ways that attitudinal barriers could or should be addressed. They shared how, through participating in this project, their own awareness of the issues they faced as well as those faced by others came to the forefront. One participant stated: *"When I started the project at first I had ideas of what to take of course but I got to about two or three photos and...it seems like I started taking more and more pictures and noticed the barriers that I didn't notice before just because I had just kind of put them away but once I actually took the time to identify them I'm like oh yeah, you know, I kind of gave that extra thought. So it was really a positive kind of... just taking those pictures and being able to share them and*

hopefully remove some of those barriers."

Consciousness-raising led participants to generate ideas for addressing negative societal attitudes through the use of photos to promote awareness of disability rights, to promote examples of good accessible design, and to raise greater societal awareness. Through photos, participants were able to clearly depict injustices in their environments. When participants identified that their rights were curtailed, they believed that the photos could be used as a visual means to create an increased awareness of the barriers. They felt that they, as young adults with disabilities, had much to offer in terms of raising awareness of barriers faced as shared by one participant: *"I think having a disability itself makes you more considerate of all disabilities. No matter what disability someone has you can kind of sympathize with their experiences because whatever their specific barriers are, you have your own barriers. And I think that makes it, if you went to design something you would be more considerate"*.

Participants also believed the photos could be used to promote positive actions and behaviours, for example as a way for businesses to market their accessibility. One participant suggested a business might say: *"Our store has employees that know sign language, or our store has bathrooms that are big enough, or our store has no barriers to getting a product off of a high shelf, or pressing a button that's very hard to press. Things like that."*

DISCUSSION

Despite growing societal recognition of the importance of creating physical accessibility in the built environment, attitudinal barriers to participation continue to perpetuate in society. Young adults with disabilities who use AT recognize that AT is a visible sign of their disability and experience attitudinal barriers in both overt and subtle ways. Individuals experience ongoing stigma based on assumptions, ignorance and lack of awareness. The theme of impatience is one that has not been well-established in the literature. In a society that values immediacy and expediency, added time that is required to engage in or

complete daily activities by some AT users can be perceived by others as an inconvenience. Addressing the nature of this societal attitude will require novel strategies.

Through the process of engaging in photovoice, young adults were able to focus on their own taken-for-granted situations and hone in on how certain aspects of the environment were instrumental in curtailing their participation experiences. Importantly, the photos provided a means to depict and discuss attitudinal barriers, barriers that are ordinarily invisible to the general public.

The social action aspect of photovoice was evident in the focus groups, when the young adults began to generate ideas for addressing attitudinal barriers through societal consciousness raising, consistent with the benefits realized through this process (Woodgate, Zurba & Tennent, 2017). The act of engaging in the focus group resulted in group discussions on ways to collectively address attitudinal barriers, such as by promotion and celebration of the efforts of business owners who addressed accessibility in positive and meaningful ways.

CONCLUSIONS

Attitudinal barriers towards individuals with disabilities who use AT may be one of the most difficult, yet important, barriers to address and resolve. Capturing the ideas of young adults with disabilities related to their perspective on societal attitudes through photos helped to make an intangible barrier such as a negative attitude, tangible. Drawing on the perspectives and recommendations of young adult is essential in addressing this challenging participation barrier faced by AT users.

REFERENCES

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2),77-101.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Los Angeles: SAGE Publications.
- Lindsay, S. (2015). A scoping review of the experiences, benefits, and challenges

involved in volunteer work among youth and young adults with a disability. *Disability and Rehabilitation*, 38 (16), 1533-1546.

Ripat, J.D., & Woodgate, R.L. (2012). Self-perceived participation among adults with spinal cord injury: a grounded theory study. *Spinal Cord*, 50(12), 908-914.

Skär, L. (2003). Peer and adult relationships of adolescents with disabilities. *Journal of Adolescence*, 26:635-49.

Statistics Canada. (2012). Disability in Canada: Initial findings from the Canadian Survey on Disability. Available: <http://www.statcan.gc.ca/pub/89-654-x/89-654-x2013001-eng.htm>

Stewart, D. (2006). Evidence to support a positive transition into adulthood for youth with disabilities. *Physical and Occupational Therapy in Pediatrics*, 26(4), 1-4.

Wang, C., & Burris, M.A. (1997) Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior*, 24(3), 369-87.

Woodgate, R., Zurba, M., & Tennent, P. (2017). Worth a thousand words? Advantages, challenges and opportunities in working with photovoice as a qualitative research method with youth and their families. *Qualitative Social Research*, 18(1). Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/2659/4045>

ACKNOWLEDGEMENTS

This research was funded by a Canadian Institutes of Health Research Grant (MOP-97792). RLW is also supported by a Canadian Institutes of Health Research Applied Chair in Reproductive, Child and Youth Health Services and Policy Research (Grant#: CIHR APR - 126339).