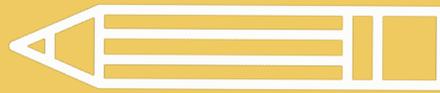


DESIGN METHODOLOGIES & ETHOS IN DISABILITY

RESEARCH SNAPSHOT

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The subject of design is one that dominates the disability literature (Williamson, 2019, p. 4). Throughout the past number of years, there has been a push among researchers and advocates to think critically about the ways in which design is executed and by whom (Williamson, 2019, p. 8). The call for significant change in design "took hold of the medical, legal, and social mainstream of the twentieth century" (Williamson, 2019, p. 13). Design has taken on a central role in the 'normalization' of disability (Williamson, 2019, p. 15). Each of these design methodologies and ethos has had an essential impact on built and design environments; however, there is still a considerable need for progress. Importantly, these design methodologies and ethos bring to light the significance of understanding that in today's society, it is normative that environments and technologies are designed for people with disabilities, not by people with disabilities.

Accessible Design: When introduced over half a century ago, 'accessible design' revolutionized the built environment (Williamson, 2019, p. 13). Design that is "usable for people with physical, sensory,



and cognitive disabilities" has become a norm in most North American architecture (Williamson, 2019, p. 13). In fact, "legal and social mandates for disability inclusion have brought about changes in nearly every public space and influenced a new range of forms in office equipment, household products, and personal technologies" (Williamson, 2019, p. 13).

However, more recently, accessible design has been defined as "design that meets prescribed code requirements for use by people with disabilities," merely as a checklist item (Story, 1998, p. 4; Williamson, 2019, p. 322). Accessible design can, and often does, "segregate people with disabilities from the majority of users" (Story, 1998, p. 4). While attempting to be progressive, accessible design is founded on the underlying principle that there are "two different kinds of people: the normal population and the population diverging from normality" (Iwarsson & Stahl, 2003, p. 60). Many of the designs that result from the 'accessible design' principles are done so as an afterthought, and are often ineffective and burdensome to use (Williamson, 2019, p. 15). Accessible design principles can also be incredibly stigmatizing and costly (Story, 1998, p. 4).

Accessible design is also highly criticized because it seems to assume that there is "some level of function that can be called 'minimally acceptable'" (Iwarsson & Stahl, 2003, p. 58). Furthermore, many of the adjustments made to accommodate for 'accessible design' only considered mobility limitations, and do not account for differences in communication, comprehension, or social dynamics (Williamson, 2019, p. 15). Many scholars have argued that the principles of accessible design are embedded in the biomedical model of health, advocating for the development of 'cure-based' solutions to disability, rather than identifying that disability is socially determined and defined (Monteleone, 2018, p. 135).

Inclusive/Universal Design: In 1985, a famous architect named Ron Mace, one of a few architects that used a wheelchair himself, coined the term 'universal design' (Hamraie, 2012, p. 5). Universal design describes a methodology where everything is "usable by all people" (Mace, 1985). Universal design requires the creation of flexibility in the underlying infrastructure, so that it can be used by everyone regardless of ability, skill, experience, or physical needs (Mankoff, Hayes, & Kasnitz, 2010, p. 6). The emphasis established by universal design is the creation of something that requires no adaptation, and whose design features go unnoticed (Story, 1998, p. 4). Universal design is "based on the principle that there is only one population, comprised of individuals representing diverse characteristics and abilities" (Iwarsson & Stahl, 2003, p. 61). Many have described universal design as a proof of the validity of the social model of disability, demonstrating that the built environment "privileges certain bodies and excludes others by producing barriers that construct disability" (Hamraie, 2012, p. 2).

In order to standardize the expectations of universal design, the Centre for Universal Design at North Carolina State University established seven key principles (Story, 1998, p. 7). These principles include equitable use, the flexibility of use, simple and intuitive use, easily perceptible information, high tolerance for error, low required physical effort, and significant size and space for approach and use (Story, 1998, pp. 8-10). Universal design is industrially harnessed by designers and architects as an effort to improve aesthetic appearances, with many of these designers simply 'glossing over' disability (Williamson, 2019, p. 325).

While universal design marks a significant change within disability rights movements, there has been increasing criticism of this design methodology in recent years (Hamraie, 2012, p. 3). One of the central areas of concern within the critical disability movement is that universal design in its current marketed state attempts to erase disability (Hamraie, 2016, p. 301). Further, although universal design



at its core advocates for the creation of a "more just world for everyone," it may also result in the shifting from a disability-neutral stance to the further stigmatization of people with disability (Hamraie, 2016, p. 302). Therefore, many disability scholars and activists are advocating for a type of design that "embraces, preserves, and celebrates diversity, rather than one that promotes its elimination" (Hamraie, 2016, p. 305).

User-Centered Design: User-centered design prioritizes the user's needs from the very beginning of the design process all the way to the end (Still & Crane, 2017, p. 1). In fact, "user-centered designers begin collecting feedback before anything is even designed" (Still & Crane, 2017, p. 1). Ten core principles guide universal design (Still & Crane, 2017, p. 44). These principles include requirements that the users are involved often and early on (Still & Crane, 2017, p. 44). User-centered design declares that "at the beginning of development, during rollout, and even after a product has gone live, users should be included" (Still & Crane, 2017, p. 46). In addition, user-centered design requires that designers consider the real-world environment constantly throughout their design process (Still & Crane, 2017, p. 44) Further, user-centered design must be kept simple when possible, must give users control, must treat users as equals, rely on verification, and discover before designing and delivery (Still & Crane, 2017, p. 44). Lastly, user-centered design must remember and plan for emotion because "people feel as much as they think" (Still & Crane, 2017, p. 44). This type of design is particularly prevalent within Brain-Computer Interface (BCI) studies and designs (Schreuder, et al., 2013, p. 79). As a very complex technology, each BCI has to be specifically designed to meet the needs of specific individuals (Schreuder, et al., 2013, p. 79).

Scholars have presented that there are "six degrees of user participation ranging from no involvement to total involvement" (Draffan, Idris, Abi, & Wald, 2016, p. 96). The first degree is 'non-involvement', and the second is 'consulted and informed' (Draffan, et al., 2016, p. 96). Most user-centered design takes place at the second level of participation in which the technology designers consult with stakeholders, people from specific disability communities, and rehabilitation professionals to produce a product that is beneficial to the user (Rogers & Marsden, 2013, p. 54). As a result, many scholars have also argued that user-centered design methods "do not go far enough in democratizing the creation of technology" (Rogers & Marsden, 2013, p. 54). Instead, the argument is that research and product design should involve the end-users as key decision-makers and designers, not simply as consultants (Rogers & Marsden, 2013, p. 54).

Participatory Design: Participatory design stems from the fourth and fifth degrees of user participation, as described by Radermacher (2006). The fourth degree is "researcher-initiated, shared decisions with participants" (Draffan, et al., 2016). Within this type of design, "participants are involved with the design from the initial stages" (Draffan, et al., 2016, p. 96). The fifth degree of user participation is "participant-initiated, shared decisions with the researcher" (Draffan, et al., 2016, p. 96). In this type of design, the "participants initiate and design the project with the assistance of a researcher" (Draffan, et al., 2016, p. 96). The fifth degree of user-participation has been actualized in studies through the use of pre-focus groups who inform researchers of their needs, priorities, and preferences before the researchers or designers begin to conceptualize their understanding of user needs (Kinney, Goodmin, & Gitlow, 2016, p. 95). This type of design method "positions designers, researchers and users equally as experts of their own experiences" (Baldwin, Hiarno, Mankoff, & Hayes, 2019, p. 4). Participatory design is an example of an overt design methodology. Further, participatory design brings to the forefront the significance of envisioning and actualizing the users, the people with disabilities, as the primary designers; instead of the more normative assumption that the designers are acting on behalf



of the wellbeing of the users (Baldwin, et al., 2019, p. 4).

Participatory design has also become a means of knowledge production in itself (Bodker & Kyng, 2018, p. 6). This type of design methodology is mobilized into action in a number of different ways, including participatory action research, participatory research, community-based participatory design, and other outputs as well (Halskov & Brodersen Hansen, 2015, p. 82). In its initial development, participatory action research and similar knowledge outputs were depicted as creating a conflict with traditional research and design methods (Halskov & Brodersen Hansen, 2015, p. 88). However, it is now better understood as creating a 'polyvoiced perspective', one that allows design to more accurately meet the needs of its users and potentially leading to an improved quality of life (Halskov & Brodersen Hansen, 2015, p. 89).

Some authors have, however, cautioned that while participatory design does "bring users into the design process, researchers need to adapt to the ability of their target audience" (Baldwin et al., 2019, p. 4)

Emancipatory Design: This type of design falls within the sixth degree of user participation as described by Radermacher, but is more accurately described as a design ethos (2006). Emancipatory design is "participant-initiated and directed" design (Draffan et al, 2016, p. 96). In this type of design, the "users initiate, design, and direct the project" on their own and have complete control over the design and decision-making processes (Draffan et al., 2016, p. 96). Emancipatory design involves the "full participation and complete control [of the users] over the research [and design] process" (Seekins & White, 2013, p. S24). Further, emancipatory design advocates for the inclusion of diverse voices, "throughout the research process" as a means of recognizing that "disability is not simply a biomedical condition but a social and political identity" (Monteleone, 2018, p. 135). Additionally, emancipatory design is praised for being both empowering and reciprocal (Monteleone, 2018, p. 137). Most importantly, emancipatory design allows for design decisions to be made by those that are most affected by these decisions. By permitting individuals with disabilities, or specific needs, to design the environments in which they prosper, and the technologies that allow them to succeed, design decisions can best represent the needs of the users.



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