

Virtual Communities: Empowering People with Disabilities to Wear Multiple Digital Hats

Stream: Identity in Communities and Networks

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Abstract

This paper examines how people with disabilities construct their identity in virtual communities. The changing disability discourse resulted in communities of practice that lend themselves to a collective identity, however virtual worlds such as *Second Life* (www.secondlife.com), allow users to experience multiple identities through the creation of avatars. The purpose of this discussion is to consider the benefits of exploring multiple identities in virtual worlds and argues that creating an avatar free from impairment cues removes the visual perception that leads to stigma and discrimination, and that empowerment comes from controlling the aspects of self that are revealed through self-presentation. It is hoped that this discussion will inform virtual community members of the benefits of experimenting with identity, and that experiencing a parallel digital life as an able-bodied or non-human persona does not compromise the values of community identity.

Keywords: virtual community, identity, disability, avatars, self-presentation

Discussion

I am real here in this unreal world, and I notice that, after talking to many others here, the community we have lost in our 'normal' lives is starting to return. I am not quite so invisible now. I am not the feared leper you think will infect you. I am your neighbor, your work colleague, and the person who travels on the same bus as you every day. I am no longer hidden. I am part of a community, and I love it. (Stewart et al, 2010, p.257-258)

Historically people with disabilities have been excluded from their communities of birth - family, neighbourhoods, schools, and society at large. As the disability discourse changed from a medical focus of institutionalisation, treatment and cures to a social model, communities of practice formed that affirm the rights of people with a disability to live a life free from discrimination, prejudice, and barriers to participation. Access to these communities of support means having to identify as a person with a disability. This paper discusses community identity for people living with disability; the presentation of self as avatars online; overcoming disability stigma to build relationships; and argues that virtual communities empower people with disabilities to decide how their identity is portrayed by choosing whether their avatars include visual representations of impairment or disability.

Unlike communities that are defined by geography, locality and physical spaces, virtual communities are recognised as social systems that involve networks of people communicating online (Katz et al, 2004; Porter, 2015; Wellman & Gulia, 1999). Discussions about virtual, or online communities, are often polarised, and a resentment of modern day computer mediated lives are dismissed as “impersonal illusions of community” (Katz et al, 2004, p. 319) compared to the nostalgia for the traditional community of localised villages and neighbourhoods with face-to-face interaction. However, there is no such yearning within disability communities where the past consisted of institutionalisation that led to the physical segregation of people with disabilities from society, and discrimination against those who were seen as sick, impaired or “a deviation from normality” (Forman et al, 2011, p.4). Wood and Bloustien (2016, p.108) note that

the disability rights movement provided a “collective identity for people who share common experiences” of resisting the social barriers that define their disability. Community support, both material and psychosocial, is also critical for people living with impairments, and is best supported by members that “share social ties and common identity” (Scotch, 2015, p.15). However, the concept of community identity is complicated further as some people with impairments resist being defined as disabled, opting instead to identify by other aspects of self, such as gender or ethnicity, or preferring to identify as being part of a linguistic and cultural minority. Members of the deaf community, for example, embrace sign language as a recognised official language, and people with Autism Spectrum Disorder (ASD) may identify as being “members of a neurodiverse culture” (Wood & Bloustien, 2016, p.108). In defining ‘identity’ beyond names, labels, and means of identification, the term refers to a “person’s conceptualisation of self; the ways in which subjectively people perceive or experience themselves as individuals” (Childs, 2011, p.14). Furthermore, Turkle (1997) challenges the notion of identity as being unitary and suggests that virtual worlds that allow people to explore multiple selves in parallel lives are a healthy aspect of normal psychological development. People wear many hats in their everyday life, and often cycle through the role of parent, partner, co-worker, and colleague. Goffman’s theories of social performance describe a theatrical metaphor for identity-as-performance where individuals construct a ‘front stage’ space that is observable to the public and a private ‘backstage’ area; a distinction that is increasingly blurred in online immersive environments as roles are performed in a public space entered into from private spaces (Pearson, 2009; Gilbert et al, 2011). Healthy individuals are resilient and have a capacity for joy that comes from nonpathological “multiplicity as a conscious, highly articulated cycling-through [multiple roles]” (Turkle, 1997, p. 79). Virtual communities give people the opportunity to practice different “presentations of self” (Pearson, 2009, para 30) and construct their identity relative to the community through playful role-play and self-expression “without compromising the values [associated] with [the] “whole person”” (Turkle, 1997, p.80). People with disabilities, therefore, benefit

from exploring their identity through multiple roles in virtual communities, without compromising their collective identity as a member of a disability community.

In virtual communities, members adopt an online persona with the option of customising their avatar's appearance and physical attributes. The word 'avatar' is derived from a Sanskrit word that "traditionally refers to the reincarnation of a deity within the physical world" (Peachy and Childs, 2011, p.1). In taking the form of an avatar, a person crosses from the 'real' to the digital, however Turkle (1997, p.79) argues that "for virtual reality to be interesting it has to emulate the real ... you have to be able to do something in the virtual that you couldn't in the real". In the renowned virtual world of *Second Life*, regular users are known as 'residents', emulating the role of residing, or existing, in a virtual community with other people and through their avatars all users can walk, run, fly, dance, teleport to new locations and participate in a myriad of social activities that they may not experience in the real. *Virtual Ability* (www.virtualability.org) is an example of an online community that operates in virtual worlds such as *Second Life*. With over 1000 members globally, it was specifically created for people that identify as having a physical, mental or developmental disability with the purpose of offering support, resources and companionship within the virtual world. In-world the community provides training on how to customise avatars, how to use assistive technologies to communicate using text or voice, and how to move through the world to interact with other users. It also runs social events and offers a platform for educational and medical conferences and presentations. Some community members that identify as having a disability alter their avatar's appearance to reflect impairment or disability, for example, amputees may edit their avatar body shape, use a wheelchair provided for free by *Virtual Ability*, dress in clothing designed for amputees, and modify their avatar movements and mobility. Others choose to appear to be completely able-bodied or disguised as non-human or anthropomorphic characters. The response to this choice is mixed as "[s]ome feel an uncomfortable sense of fragmentation, some a sense of relief. Some sense the possibilities for self-discovery, even self-transformation."

(Turkle, 1997, p.77). The ease with which users can create multiple avatars and change appearance may make people with disabilities feel torn between creating avatars or visual representations that convey their actual physical attributes, impairment or aides, and avatars that remove visual cues and allow anonymity.

People with disabilities continue to face discrimination and prejudice in everyday life, due to the visual perception of their physical differences or their distinctive social communication methods. Forman et al (2011) proposes a disability schema that dictates how people form judgment and perceptions about people with disability by attaching meaning to information they have been taught or observed over time which stigmatises and stereotypes individuals. A person in a wheelchair, for example, becomes associated with the wheelchair, and a disability schema is constructed “based on a perceived condition or disability” (Forman et al, 2011, p. 3) that leads to internalised notions of the individual’s ability and sets societal expectations. Virtual environments give people with disabilities control of their projected image, and without the objectifying cues provide “freedom from embodied identities” (Forman et al, 2011, p.4) giving participants “more control over the timing and content of their self-disclosures [and] allows relationships to develop on the basis of shared interests” (Wellman and Gulia, 1999, p.15) free from stigma. A study conducted by Stewart et al (2010) describes the *Second Life* experience of people with disabilities as shedding visual cues which results in feeling “as though they have escaped the confines of their disabilities” (Stewart et al, 2010, p.255) and states that disclosures of disability are not met with the same reaction as they would be when face-to-face because the disability cues do not exist in the virtual world. Timothy Carey (one of the co-authors in this study) has Duchenne Muscular Dystrophy (DMD) and became a wheelchair user at age 8, and by 36 had only slight movement of his fingers.. With the exception of attending medical appointments, he rarely leaves the house; however, as a professional computer programmer and web developer he embraced *Second Life* and “as a person with a disability, he was amazed at how liberating it felt to have his avatar walk, fly, and socialize”

(Stewart et al, 2010, p.255). Despite having difficulty standing and running as a young child, his disability did not draw attention until he needed a wheelchair. Timothy is an active member of multiple communities and non-profit organisations that assist people with disabilities in-world. He fulfils his childhood dream of being a pilot by providing free tours in *Second Life* in his virtual airplane or helicopter, appearing as an able-bodied avatar. As a computer programmer he designs and creates assistive technologies, such as inventing an object to help people with a disability that cannot use a mouse, and a device to enable an avatar to use sign language and assist people who are hearing impaired. From building, to landscaping, cooking, taking field trips with friends, dancing, and participating in educational activities, Timothy engages in activities in *Second Life* that “enrich and add meaning to his life and give him the opportunity to meet people” (Stewart et al, 2010, p.256). Using an avatar in virtual worlds allows people with disabilities to eliminate disability stigma and immerse themselves in activities and experiences free from discrimination and barriers of everyday life while actively participating in a community.

The ability to choose and control self-presentation and identity in virtual communities empowers people with disabilities to disclose at will and allows strong ties and relationships to develop. Despite the closure of institutions that housed people with disabilities, many continue to face social, cultural and political isolation; regularly deal with harsh government bureaucracy; and face discrimination and prejudice in everyday life, often without the support of extended family (Bloustien & Wood, 2016; Scotch, 2015). Bloustien and Wood (2016, p.102) believe that “membership of an online community specifically designed for people with disabilities, together with the ability to change one’s appearance and mobility at will ... creates a greater sense of belonging and inclusion”. People are social beings that seek companionship, emotional and social support, and a sense of belonging, which Wellman and Gulia (1999) state can be provided online through community ties. They emphasise the significance of weak ties as “important sources of information, support, companionship and a

sense of belonging” (p.10), whereas strong, intimate ties are created and sustained online by frequent, long-term contact that facilitate and reciprocate support, and over time these online relationships grow to be as intimate as in-person relationships. Virtual communities provide opportunities for weak ties to develop through the dissemination of information about disabilities, training in the use of assistive technologies and a network of educational and medical resources. Computer mediated communication also allows people “to transmit information and build relationships among large groups of physically disconnected individuals” (Viluckiene, 2014, p.454). For some people with disabilities communication barriers can hinder the strengthening of ties and virtual worlds provide the anonymity and environmental controls to aid people in their communication and interaction with the world. For example, people with ASD can control an avatar and use the virtual environment to remove excessive stimuli to reduce barriers to communication and minimise sensory overload. Stendal & Balandin (2015, p.1592) surmise that communicating and interacting online “while the individual is physically located in a safe and known environment, may create a sense of safety and control” which helps people with ASD to overcome communication difficulties. Empowerment comes from choice and control.

Individuals that identify as a person with a disability have access to communities of practice that form the foundation of community identity. Virtual communities allow members to develop ties and build relationships online, while also exploring their identity through multiple roles in virtual worlds. With the choice of portraying their avatar selves with visual representation of impairment or choosing to create an avatar free from impairment cues that lead to stigma and discrimination, people with disabilities can compartmentalise their disability identity. This choice of self-presentation empowers people to control how they are perceived, how they interact with others, and to choose which aspects of self they reveal. Identifying as a person with a disability should not limit the individual from wearing multiple proverbial digital hats and existing in a parallel digital life,

where they can experiment with their identity, participate in online communities as an able-bodied or non-human persona, and experience activities that enrich their lives.

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