

# Chapter 2

## The Myth of Neutral Technology

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**Abstract** The meaning that assistive technology (AT) holds for the user is a key determinant of whether the device will be used or abandoned. Two concepts, stigma and liminality (existing in a state of transition), are used to frame users' perceptions of the assistive technology they use, as generated through research projects investigating aspects of assistive technology use. Implications of the meaning of AT to the design and selection process are described. Assistive technology that is seen as a tool, as just another way of achieving a desired activity is much more likely to be assimilated into the user's daily life. Technology perceived in this manner enables people to share activities with others and augment their personal abilities. Alternately, technology can be seen as a visible sign of disability, reinforcing stigma associated with a disability and the perception of the AT user as existing somewhere between health and illness. Individuals with this view of technology may avoid or resist use of technology, resulting in avoidance of meaningful activities and both social and physical isolation. These findings support the conclusion that technology is not neutral. Inclusion of users in both the design and selection process and understanding the meaning that AT use holds are integral to the development of assistive technology that achieves the desired outcome of enabling participation in daily life.

Meaning is at least as powerful an influence as skill in determining whether a device will be incorporated by an individual as a useful tool or discarded as excess baggage [9].

Assistive technology (AT) can augment or replace function in many individuals with disabilities, enabling them to participate in daily activities in their communities. The functionality of AT can be very appealing to

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designers, researchers and prescribers, with the potential to create ever more complex technology to address physical, cognitive, or sensory impairment without the necessary consideration of the influence of technology on the user's self-perception. Focus on device functionality may limit understanding that the technology holds meaning to the consumer and significant others, in other words, that technology is not neutral. Meaning is often a factor in whether technology will be used or put into the closet. This chapter will explore various meanings that users ascribe to AT and the implications of these meanings to the design, recommendation, selection and evaluation processes. Two related constructs will guide this exploration: stigma and liminality.

Stigma was described by Goffman [2] as possession of an external characteristic that discredits the individual. The presence of a physical impairment becomes the source of a spoiled identity. He discusses the concept of "spread" where the discrediting attribute attains a "master" status so that it defines the individual, and all other personal accomplishments or attributes are ignored. Stigma is context dependent; environments of various physical, social, or institutional elements either reinforce or limit the perception of stigma.

Liminality is an anthropological term that conveys the notion of transition and is often used to characterize the period of development of moving from childhood to adolescence. It frequently involves a change of status, social isolation, and/or physical removal of an individual. Liminality for a person with disabilities has been described by Murphy [7] as feeling distant from society, although not specifically excluded from it; as being between health and illness. Murphy's 1990 book *The Body Silent* describes his transition from full participation in society as an academic anthropologist to living with the physical abilities that resulted from a spinal cord tumor that caused increasing paralysis. His account ably describes the experience of being and becoming a person who has a disability [10].

These two constructs, stigma and liminality, are used to frame the discussion of the meaning of assistive technology for individuals who use it, including the consumer and their families or other caregivers. They will be applied to the following ideas to give context to results of various research projects that included a component of the meaning that individuals ascribe to the technology they use and to promote awareness in AT designers and prescribers of why a device that is anticipated to be of benefit to the user in their daily life is not embraced or is even discarded.

## 2.1 Source of the Data

The following ideas come from various research projects: a qualitative exploration of how persons with disabilities chose to complete daily activities, a phenomenological study of the lived experience of using AT when assisting

a significant other, and design projects that involved consumers (broadly understood) at all stages of the process as well as from the literature [6, 5]. This work, in part, derives from concern about the rate of abandonment of AT and the associated costs – monetary, time, and social participation – to the consumer, others in their social sphere, and society.

## 2.2 Key Ideas Related to Meaning and Assistive Technology

Not surprisingly, the meaning of technology conveys both positive and negative/enabler and barrier notions. Two broad perceptions of technology will be discussed to illustrate the meaning that AT can hold for consumers: *assistive technology as a tool* and *assistive technology as a visible sign of disability*.

### 2.2.1 Assistive Technology as a Tool

Some assistive technology users, mostly those who are experienced users, view their technology as a means to complete an activity. The meaning ascribed to the AT was no different than any other tool or technology used in daily life. For example, participants in a project exploring how individuals chose to complete daily activities talked about sharing opinions on the best chair components for their sport along with wheelchair maintenance and modification activities. These discussions had the flavor of cyclists discussing the latest cycling technologies. The AT was simply a tool that enabled them to compete in a sport they loved.

Participants in both qualitative studies indicated that assistive technology facilitated their ability to engage in desired activities. Participants in one study indicated that access to AT was a primary factor in enabling a significant other to return home, as seen in the following quote [6]:

“[lift] helps him and me together to do it [daily care]... Without [the lift] I would not be able to handle [husband].”

For many participants in these studies, the technology had faded into the background of their lives. They did not speak of the challenges posed by the technology but did describe the constraints imposed by the environment that was not accessible due to their use of the technology.

Assistive technology can provide a means to share activities. While the decision to obtain a powered wheelchair is not made lightly, it can provide independent mobility that results in a couple being able to walk side by side as they go about daily tasks rather than one partner being dependent on the

other to propel the chair. Technology levels the playing field, a point often made in reference to computer access technology. As one study participant indicated [5]:

“We are all given the exact same abilities in the digital environment ... And when you are online, nobody knows you have a disability so it [the disability] never really comes into it—it has a very big appeal to me.”

When technology is viewed as a tool, as something that is a necessary and integrated part of daily life, it becomes an enabler of activity. However, far too often, technology is seen as a reminder that the user cannot participate in their community as they wish.

### *2.2.2 Assistive Technology as a Visible Sign of Disability*

When assistive technology is perceived to signal to others that the user is disabled, it can become a barrier to participation in daily activities or be abandoned. The technology reinforces a discrediting attribute and enhances the perception of stigma. The technology becomes the focus of attention rather than the person using the technology. The influence of the technology on others' perceptions is seen in the following quote by a 22-year-old university student [5]:

“People see the chair and make certain perceptions and there's certain understanding of what it means to be disabled.”

Some people will avoid the use of technology and either not go to certain community locations or, if they do so, will limit what they do because they do not want to be seen as someone with a disability. The following quote from a 25-year-old social worker illustrates this point [5]:

“the other night...I chose to like suck it up and walk the best I could without my cane, because I would rather them not see me like that.”

Similar ideas were expressed by people who refused to use a white cane or a powered wheelchair because of the image of disability these devices conveyed.

AT can be seen as a source of isolation in a number of ways. It can physically isolate the user as in the experience of a woman who reported that she and her husband were located in a back corner of a restaurant, out of sight of other patrons or when people who use wheelchairs are relegated to specific areas of a theatre or stadium that are accessible, but that do not necessarily allow them to sit with their companions. Technology such as augmentative and alternative communication devices or wheelchairs, by the nature of their design and use, are an actual physical barrier between the user and others in their environment, reinforcing a state of liminality.

More troubling than the physical barrier is that AT can be socially isolating. A common comment, reflected in the notion of wheelchairs as portable seclusion huts [8], is that the technology distances the user from others in their environment. This physical barrier then becomes a psychological barrier. People who use technology frequently report experiences such as service providers speaking to their companions rather than themselves in social circumstances, such as when they are making purchases.

## 2.3 Implications for AT Design and Selection

The collective results of these projects reinforce the notion that assistive technology is not neutral. It carries a meaning to the user, others in their social sphere and the community at large. When that meaning is a positive one, AT is more likely to be incorporated into daily life. These key themes and the feedback obtained during the design process have important implications for AT design and selection. They suggest that technology that reduces the impact of stigma and that enables the user to participate and thus feel less isolated will be more acceptable and useful to the consumer.

Successful technology fades into the background of daily life. It becomes just another way of completing a desired activity. Feedback provided by children, parents and formal caregivers on design and function of AT in the development of three types of seating projects [1, 4] revealed considerable consistency across projects on perceptions of features that defined a desirable device. Many consumers wanted a device that was aesthetically pleasing, was simple to use and easy to maintain. Flexibility of use for different activities and in different environments was another key feature.

The design and appearance of the device carry meaning for the individual and should not be overlooked in the development or recommendation processes. Color of the device may not seem like an important feature over others such as the ability to tilt a wheelchair seat or adjust a guardrail on a bed. However, materials used to make a device and attention paid to the aesthetics can result in a device that blends into the user's environment, or not. A device that looks similar to those available on the consumer market reinforces the perception that the user is healthy and potentially reduces isolation (ideas related to liminality).

The meaning of technology is a particularly important consideration for older adults, who form an increasingly larger proportion of our population. Many older adults want to remain in their own homes and will incorporate technology that does not make them feel vulnerable and allows them to feel more secure, safe and less of a perceived burden. Johnson, Davenport and Mann [3] explored the perceptions of older adults of different smart technology used in the Gator House at University of Florida. They asked seniors whether they felt that the devices present in the house were useful to them

at this time in their life. Technology that conveyed a sense of security was more readily accepted than that which was seen as surveillance. For example, people typically indicated that sensors that would detect a fall were probably something that would be useful but not at that point in their life; in other words, the more invasive technology was less acceptable.

The collective results of all of these projects lead to one critical conclusion: the individuals seeking devices are the experts in their own lives. The individual designing or recommending a device retains expertise related to AT and a professional responsibility to the client, but does not know what is best for the user. It remains important to ask questions about what technology means to the user. The most carefully designed and prescribed technology is of no value if the intended user leaves it in the closet. Technology that is recommended without input from the consumer is in danger of being abandoned, at a cost to the user, their community, and society.

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