

Assistive Technology Use and Stigma

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Abstract: Issues related to stigma and its impact on assistive technology (AT) use with persons having developmental disabilities are addressed. While stigma has been known to be associated with presence of disability for many years, relationship between stigma and AT usage, particularly when working with families across cultures, has only just begun to be examined. Issues confronted by AT decision-making teams related to stigma include family expectations of AT, visibility resulting from use of AT in public settings, and perceptions that children will not attain important developmental skills if they become reliant on devices. While numerous approaches for AT decision-making have been implemented in the field, absence of validity and reliability data related to such approaches emphasizes importance of understanding potential influences of stigma associated with AT use. Specific areas that can contribute to stigmatization include (a) device aesthetics/cosmesis, (b) gender and age appropriateness, (c) social acceptability, (d) sublimation and professional deference, (e) teachers and acceptance of disability, and (f) universal design principles. Importance of future research that explores stigma and government policy and impact on AT decision-making is noted.

The experience of *stigma* is common among human beings (Crandall, 2000). As noted by Crocker, Major, and Steele (1998), “A person who is stigmatized is a person whose social identity, or membership in some social category, calls into question his or her humanity—the person is devalued, spoiled, or flawed in the eyes of others” (p. 504). All persons have experienced some degree of *stigmatization* at some point in their lives, whether it is feelings of isolation, alienation, exclusion, or embarrassment resulting from being different in some way.

References to the phenomenon of stigmatization of individuals having disabilities may be found throughout the professional literature (see e.g., Barker, 1948; Fine & Asch, 1988; Goffman, 1963; Gray & Hahn, 1997; and Jones, Farina, Hastorf, Markus, Miller, & Scott, 1984). For persons with developmental disabilities, stigmatization is often a reality having varying effects, including, but not limited to, (a) less than ideal treatment (Crocker et al., 1998); (b) disrupted social relations (Goffman); (c) person avoidance, anxiety,

and depression (Crandall & Coleman, 1992); and (d) a distorted self-image and resulting poor self-esteem (Wright, 1983). Some people may even attempt to hide their developmental disabilities from others to avoid the stigma (de Torres, 2002; Liu, 2001; Lopez-De Fede & Haeussler-Fior, 2002; Miller, 2002; Napier-Tibere, 2002; Pinto & Sahu, 2001).

Stigmatization has also been suggested to be associated with assistive technology (AT) usage for persons with acquired disabilities in later life (Brickfield, 1984; Luborsky, 1993; Zimmer & Chappell, 1999), often resulting in abandonment of devices. For example, elders with disabilities may choose not to implement AT that is not routinely used by the general population (e.g., wheelchairs, walkers) given the message communicated to others that they are vulnerable, or if it creates social barriers (Lebbon & Boess, 1998; Luborsky, 1993; Polgar, 2002). Persons of any age, however, can feel stigmatized by devices that signal loss of function. As one woman in her 40's born with cerebral palsy noted when surgery on her neck left her paralyzed from the neck down, resulting in the need for a more sophisticated wheelchair:

To everyone's relief, the doctor said I didn't need either the cervical collar or my corset when I used the wheelchair. I was especially

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glad, as I didn't like to look that disabled, or you could say, I wasn't accustomed to having that many people stare at me. (Scherer, 2000, pp. 93-94)

Hearing aids are perceived as stigmatizing by many aging persons, but also to those who require them at younger ages. One woman said about the need to wear hearing aids at age 20:

But after getting my hearing aid, every time I went outside I wore a scarf, so that if the wind blew, people would not see that I wore a hearing aid. You just didn't see twenty year-olds wearing a hearing aid. It was not an easy thing to get used to. (Scherer, 2003)

The choice to wear a hearing aid and feel stigmatized, or not wear a hearing aid and possibly miscommunicate is a dilemma with strong implications for one's self-esteem. Additionally, the personal and social aspects of coming to terms with a hearing loss are often stressful. When under stress, one's ability to hear and participate in interactions becomes compromised. Thus, avoidance of AT can have implications for social participation and both mental and physical health (Scherer, 2003):

It's been very hard over the years. . . because I had gotten into so many situations where I didn't fully understand what is being said. And I'd say maybe the wrong thing or respond to something I heard, but the subject had already changed. And when you feel off-the-track and lost so often, you begin to lose your sense of being okay (Scherer, 2003).

When working with individuals with developmental disabilities, it is important to explore their expectation of AT use and readiness for that use. Even when a person with a disability may be ready to, and even excited about, using AT, stigma has been suggested to be associated with choices made by families of school-age students with disabilities to not implement AT devices due to perceived increased visibility or attention received when children use devices in public settings (Brooks, 1998; Smith-Lewis, 1992). Stigma has

also been reported to be associated with AT due to fears that the child will not attain important developmental skills if they rely on a device (Allaire, Gressard, Blackman, & Hostler, 1991; Berry, 1987). As noted by Brookes (1998): "Assistive devices become a signal because the sight of a person using assistive technology sends a message that this is not an ordinary person and that one needs to behave differently around this person" (p. 4). Given that a person's self-esteem and self-image are developed across time through interactions with others (Crocker & Quinn, 2002), presence of AT may define those interactions and contribute substantially to a person's self-image (Scherer, 2000).

While the literature has references to the *stigmatization* of individuals having developmental disabilities (see e.g., Barker, 1948; Fine & Asch, 1988; Goffman, 1963; and Gray & Hahn, 1997), little information exists that explains *why* these persons feel stigmatized, and what the potential impact of stigma is on professional recommendations regarding service delivery. This becomes problematic given the relative 'youth' of the field of AT (Edyburn, 2000). Numerous models have emerged to assist AT teams in decision-making about devices and services for persons with disabilities (Bowser & Reed, 1998; Chambers, 1997; Institute for Matching Person and Technology, 2000; Melichar & Blackhurst, 1993; Williams, Stemach, Wolf, & Stanger, 1995; Zabala, 1998). However, Watts, O'Brien, and Wojcik (2003) note that little reliability and validity data are currently available to support effectiveness of such approaches for AT decision-making. Adding to this problem are (a) the expectations of family (and user) input and active participation in decision-making processes that is deeply embedded in many decision-making models, and (b) lack of sensitivity on the part of teams to cultural and family issues during AT decision-making (Kemp & Parette, 2000; Parette, Brotherson, & Huer, 2000; Parette & Huer, 2002; Parette & McMahon, 2002).

The remainder of this paper focuses on issue areas related to stigma and its impact on the AT decision-making process, with recommendations for future research for consideration by professionals. Specific areas addressed are (a) device aesthetics/cosmesis,

(b) gender and age appropriateness, (c) social acceptability, (d) sublimation and professional deference, (e) teachers and acceptance of disability, and (f) universal design principles.

Device Aesthetics/Cosmesis

Levels of comfort with use, even around family members, vary widely depending on how “unusual” an AT appears. Feelings of being conspicuous leave many users feeling deviant and stigmatized (Scherer, 2000). How any particular individual feels about him or herself when using AT is intimately tied to self-esteem, the degree to which the person will reach out to others and initiate relationships, and ultimately one’s social participation or withdrawal. When one isn’t involved in social relationships, it is difficult to form a sense of acceptable social behavior, thus leading in many cases to isolation (Scherer, 2003).

Gender and Age Appropriateness

While women with developmental disabilities are often very skilled in using technologies for communication, mobility, learning and the performance of daily tasks, the number of these women involved in the design and development of such products is very small. This is the proverbial Catch-22 situation: The undereducated or underemployed woman with a disability is unlikely to get the technology or training necessary to compete with her non-disabled counterparts educationally or vocationally. Without technologies, women with disabilities cannot perform tasks independently or without fatigue or enervating pain. To get the appropriate technology requires access to information about and the ability to pay for them—another Catch-22 (National Women’s Health Information Center, n.d.).

In the area of an AT’s appearance, preferences reign, and preferences of adolescents will be different from adults. Worldwide, adolescents with disabilities tend to be or are more concerned with their appearance and projected image than older adults (Scherer, 2003). Gender, age and ethnoracial differences in the use of AT have been studied to

some extent (e.g., Gitlin, 2002; and Rintala, 2002) but researchers note the need for more focus in these areas.

Recent reports from the U.S. National Council on Disability (1996) and the European Commission’s Telematics Applications Program (Ballabio & Moran, 1998) acknowledge that older individuals and women with developmental disabilities often are poorly matched with a product they need to use regularly. As they age, consumers have a clear preference for products that they do not have to think about (are easy to care for and maintain and which accommodate to them, not vice versa). When presented with a choice, consumers will select assistive devices, as they do with any product, according to characteristics that satisfy their preferences.

Social Acceptability

Many psychosocial factors impact the use or nonuse of AT, including personality, response to disability and the environment or social milieu in which technology is used (Krefting & Krefting, 1991; Scherer, 2000). Social acceptability of AT has been identified as one of the critical elements impacting whether or not a particular device is used by a person with a developmental disability and family (Pippin & Fernie, 1997). As noted by Cioffi (2002), public behavior (such as AT usage) activates cognitive, social, and motivational forces that align a person’s self-views with those of others. Of particular importance for individuals with developmental disabilities and their families may be the heightened sense of attention and evaluation engendered by the AT act (Saenz, 1994). People who feel themselves to be under greater scrutiny in social settings may feel that their behavior is more public (Cioffi), which may be at considerable odds with strongly held collectivist cultural values that emphasize group membership versus individual recognition (Hyun & Fowler, 1995; Ramirez & Casteneda, 1974). Collectivism represents a central point of departure between Western society and most traditional minority cultures (Harrison, Wilson, Pine, Chan, & Buriel, 1990). Collectivism may be particularly problematic for Euro Americans who typically place high value on independence and individualism that is so often reflected in the AT

component of service plans developed for children with developmental disabilities (Harry, 1994).

At the same time families from culturally and linguistically diverse backgrounds may want immediacy of results when AT devices are prescribed for their children with developmental disabilities (Parette & Huer, 2002). Such expectations for AT benefits may be at odds with professional perceptions regarding the appropriateness of devices in a range of milieus.

On examination of these two very different perceptions of the value of AT in social settings, one sees a strongly held perception on the part of a Euro American professional that the AT device is desirable since it promotes independence, whereas the family member is concerned with the practicality of the device. When professionals are insensitive to the social expectations of a particular AT device being considered for a child with a developmental disability, dissonance between the family and other AT team members can occur. This may be especially true of persons from culturally and linguistically diverse backgrounds who perceive themselves as 'tokens,' that is, a member of a group who feels that his or her group membership is perceived negatively by others (Crocker et al., 1998). If a person feels that they are a member of a token group (e.g., African American) they may be far more sensitive to professionally prescribed AT if it singles them out and is perceived to reinforce stereotypes held by others (Biernat, Vescio, & Theno, 1996; Schuman, Steeh, BoBo, & Krysan, 1997).

Professionals involved in making decisions about AT devices must be sensitive to both child *and* family values and preferences regarding appropriateness of device usage in social purposes. Such sensitivity will contribute to more effective AT decision-making.

Sublimation and Professional Deference

An assumption sometimes made by many AT professionals is that certain devices prescribed for children with developmental disabilities satisfy multiple users needs and thus should be used across environmental settings (e.g., augmentative and alternative communication devices; mobility aids; amplification devices;

Lindsey, 2000). Such flexible expectations of certain types of AT may reflect the long-standing *professional* perception of the importance of generalization of skills acquired in intervention settings (Matlock, Lynch, & Paeth, 1990; Meese, 1994). Of course, such multiple milieu usage presupposes that user needs and environmental demands in these settings justify use of the device (Institute for Matching Person and Technology, 2002).

Although some AT decision-making models give considerable credence to examining milieus in which devices will be used (e.g., Institute for Matching Person and Technology, 2002; Melichar & Blackhurst, 1993; and Zabala, 1998) *and* input from family members and users (e.g., Bowser & Reed, 1998; Chambers, 1997; Williams et al., 1995; and Zabala), the cultural values and preferences of family members may sometimes be at odds with those of professionals. Families may view judgments of professionals to be more important than their own (Fewell & Vadasy, 1986; McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993). This feeling of loss of power, or transfer of decision-making power to professionals who are viewed as knowing "what is best" for the family, may contribute to the loss of much valuable information during the assessment process (Parette & Brotherson, 1996).

If family members have strong culturally-based values regarding the importance of educators, that is, teachers and other professionals opinions are to be respected and not questioned, family opinions and preferences regarding AT being considered for the child with a developmental disability may not be expressed (Parette & Huer, 2002; Roseberry-McKibbin, 2002). This can result in devices being prescribed (and implemented in some settings) because families agree to professional recommendations, though it may also place families in the situation of dealing with stigma issues when devices are to be implemented in social settings. For example, Asian families typically show great respect for education professionals and may tend to be reticent in expressing their opinions if they differ from those articulated by the professionals. Rather than expressing their concerns about the stigmatizing effects of the recommended devices, family members may simply acquiesce

and publicly indicate acceptance through head nodding and agreement to implement devices, with subsequent abandonment of their use in public and social settings (Parette & Huer).

Teachers and Acceptance of Disability

General attitudes toward individuals with developmental disabilities are affected by two primary factors: (a) the amount and nature of direct contact with individuals with developmental disabilities (Gething, 1991; Nathanson, 1982; Strohmer, Grand, & Purcell, 1984; Yunker, Block, & Young, 1966), and (b) information about developmental disabilities and persons with such disabilities (Anthony, 1972; Haddad, 1974; Yunker & Hurley, 1987). Positive and negative attitudes are evidenced by the extent to which someone perceives persons with developmental disabilities as being similar rather than different from persons without disabilities. Biernat and Dovidio (2002) refer to this as the “groupiness factor,” or the extent to which the stigma is based on membership in a specific group. Positive and negative attitudes are also affected by the extent to which someone believes persons with disabilities should be treated similarly to and not differently from persons without developmental disabilities. Scherer (1996) notes that persons who look beyond disability and espouse a philosophy that “it is ultimately more important and cost-effective to enhance a person’s quality of life, not merely to restore capability, are being person-centered” (p. 85).

The growing research database on inclusion of students with developmental disabilities indicates the most critical factors for successful inclusion are attitude of the teacher, learning environment including resources, and peer acceptance (Kowalski & Rizzo, 1996; Rizzo & Kirkendall, 1995; Scruggs & Mastropieri, 1996). Bauer and Piazza (1998) noted that teachers trained both in AT and cultural diversity may be more inclined to invite a child with a developmental disability into his or her classroom environment. Teachers also have a responsibility to provide information to other students in the classroom regarding AT used by a particular child to facilitate acceptance (State of North Dakota Department of Public Instruction, 1999). When teachers assist stu-

dents in understanding the AT used by a child with a developmental disability, the negative impact of stigma can be minimized (Stuart, 1998).

Teacher acceptance becomes particularly important given the importance of examining the milieu and the challenges/supports available in each setting where AT will be used. When teacher attitudes are negative due to the stigma of the child’s developmental disability, or due to *technophobia* (i.e., persons having a fear of technology) on the part of the teacher (Scherer, 1996), challenges to effective implementation of AT may be substantive. Conversely, if teacher attitudes are positive toward the child and his or her AT due to little (or no) impact of perceived stigma, support from the teacher may be present for effective implementation of AT.

Interestingly, the extent to which some groups may stigmatize persons with developmental disabilities who use technology may be a function of the degree to which the latter group is deemed to be competing for important resources (Neuberg, Smith, & Asher, 2002). The teaching environment today is defined to a great extent by legislative and political mandates and economic assets and deficits. Teaching environments have attitudinal, cultural, and physical attributes that serve to determine composition of the student body and determine students they will teach as well as the manifest and “hidden curricula.” When teachers hold negative attitudes toward persons with disabilities based on myths and flawed assumptions that these individuals are drawing resources away from typical peers, ability of the teacher to accept the child in a particular milieu may be minimized. In such instances, teacher support in the form of awareness training and other supports may be indicated. Students require skilled and caring teachers who view technology as a tool, not a replacement, for teaching. But teachers must receive training at both the preservice *and* inservice levels regarding the choices in AT available (Edyburn & Gardner, 1999), how to choose and use the right AT for a specific educational goal, and how to best incorporate AT into the curriculum so that stigma is avoided (Scherer, 2003).

For several decades, professionals have been advocating *universal design* as a way to create products and environments that are usable for all persons in our society, regardless of age or disability (see e.g., Center for Inclusive Design and Environmental Access, 2001; and Universal Design Education Project, n.d.). Products and spaces are designed only for people with disabilities and older people will always be more expensive, appear different, and have stigma associated with their usage (Connell et al., 1997). Universal design is a concept intended to increase the market for and, thus, production of products and environments that are usable by everyone to the greatest extent possible (Mace, 1985). Mueller (1990) noted that an operational assumption of universal design is that by making more products and environments usable by a wide range of people, the need for and higher cost of specialized products and environments may be reduced—a highly desirable outcome for all consumers. Typically, accessible design tends to result in *separate facilities* for individuals with disabilities (e.g., ramps, toilet stalls) while universal design provides a single solution accommodating all people.

Ideally, application of universal design principles in design of AT would result in esthetically pleasing devices that are seamless in design (Covington, 1998). Products that are universally designed are also more attractive and may decrease abandonment as they are free from the stigma often associated with a developmental disability (Cowan & Turner-Smith, 1998; Fozard, Rietsema, Bourn, & Graafmans, 2000).

Unfortunately, as noted by Mace (1998), little or no attention is paid to the aesthetics of assistive technology and rarely is competitive marketing an issue. During the AT decision-making processes, children with developmental disabilities and their families may often be expected to use the devices selected by team members and be grateful for the improved function or support they receive despite any stigma, embarrassment, or negative image generated by the device.

Conclusions and Implications

Stigmas associated with disability and AT usage are integrally related and have the potential to substantively affect AT decision-making processes. Families from diverse cultural backgrounds who may be the focus of team decision-making bring a range of values, priorities, and preferences to these processes. Often, their perceptions of their children with developmental disabilities and AT solutions being considered will be affected to a large extent by the presence of stigma. Compounding the problem is that team members themselves, as well as others in various milieus where the AT being considered might potentially be used, may also perceive stigmas associated with children having developmental disabilities, AT, or both. In such instances, the potential of AT to reduce physical and social barriers can be minimized.

Research is needed to explore the current and ongoing effects of stigma on government policy related to AT service delivery, as well as the effects on team decision-making in schools. Each of the models for AT decision-making that have been proposed in literature must undergo reliability and validity studies of the processes associated with each model. Such data will enable refinement of assessment processes to ensure that a careful match between person and AT occurs, users' preferences and needs are appropriately and adequately addressed, and stigmatizing effects of AT use are reduced.

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