Invisible Access Needs of People With Intellectual Disabilities: A Conceptual Model of Practice

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One of the important purposes of equal rights legislation is to codify the right to equal and active participation in society for people with disabilities. Accommodating the needs of a person with a disability enables her/him to live with maximum independence, privacy, and dignity. Thus, most such laws include sections that emphasize accessibility as a significant enabler of participation.

Accessibility describes the degree to which a system, facility, or service is usable without modification by as many people as possible (Australian Government Information Management Office [AGIMO], 2008). It refers to one's ability to reach a place, move and navigate in it, use and enjoy a service, receive information, and take part in programs and activities, all in an equal, respectable, independent, and safe manner (Americans With Disabilities Act [ADA], 1990; Israeli Equal Rights for Persons With Disabilities Law — Accessibility Amendment, 2005).

Access ramps or Braille-encoded elevator panels are ubiquitous examples of common accessibility accommodations. Yet, accessibility accommodations for people with intellectual disabilities are nearly absent, as their accessibility needs are often invisible to legislators, professionals, and laypeople alike. For example, although access needs to public transportation of a person using a wheelchair are easily apparent and protected by legislation, they are virtually nonexistent for able-bodied people with an intellectual disability (Improving Mobility and Accessibility for People with Learning Disabilities in Europe [MAPLE], 2003). Yet, transportation access is reported by people with intellectual disabilities as a significant barrier to community inclusion and social participation (Fager, Perker, & Kelly, 2005).

Accessibility needs and accommodations for people with physical and sensory disabilities are covered extensively in the accessibility literature. However, while advising the Israeli National Commission on Equal Rights for People With Disabilities, I was surprised to discover that the development of similar models, guidelines, and reasonable accommodations for people with intellectual disabilities is preliminary at best (Salmi, 2007). Legislation and regulation of these issues are sparse, and most research is anecdotal and lacks a comprehensive underlying model of practice.

Although some accessibility barriers and accommodations were intuitively apparent to me based on my clinical experience, as an occupational therapist, with adults with intellectual disabilities, others were later on identified through interviews I conducted with people with intellectual disabilities, family members, and service providers (Yalon-Chamovitz, 2007). Below, I juxtapose the information garnered from the published literature with these factors to suggest a conceptual model of accessibility for people with intellectual disabilities.

Accessibility and People With Intellectual Disabilities

Accessibility is about the ability to reach and navigate a place; the opportunity to participate, use, and enjoy a service or facility; and the right to receive information. However, as mentioned above, the barriers to accessibility faced by people with intellectual disabilities are not always apparent and, therefore, require exploration and clarification. The main accessibility challenges faced by people with intellectual disability can be categorized by four domains: pace, complexity, literacy, and stigma.

Pace

Society interacts at a high speed, presenting strong demands for temporal adaptation (Hartmut, 2003). These stressful temporal demands are not fully recognized until we find ourselves in a situation of temporal stress. For example, whereas we usually react seamlessly to familiar public transportation terminals, how do we function in a

subway or bus station of a foreign country? The common response is to "leave plenty of time" to navigate the system.

Multiple studies have repeatedly shown that people with intellectual disabilities present relatively slow processing and reaction times in many different tasks and settings (for a review, see Kail, 2000). Thus, their experiences of temporal challenges are not necessarily restricted to atypically stressful situations but are a frustrating characteristic of their routine experiences and a major barrier to social participation. Traditionally, according to the medical model, people with intellectual disabilities were expected to adjust to such temporal stress, and rehabilitation efforts were focused on overcoming pace and reaction-time "incompatibility." The shift from a medical model to a social model of practice also included a shift from societal expectation for individual change and adaptation to societal responsibility for environmental change and accommodations to enable full access and participation (Feldman, 2007).

Pace and temporal demands are almost always indicated as barriers to accessibility by consumers with intellectual disabilities, family members, and professionals (Yalon-Chamovitz, 2007). However, accessibility regulations and standards provide very limited guidance with regards to temporal adaptations and accommodations (ADA Accessibility Guidelines for Buildings and Facilities, 2002).

As a rule, accessibility assessment should always include temporal aspects. Pace accommodations should be applied to both environmental design and procedures of service provision. Research should establish solid guidelines for temporal accommodations, and advocates must work hard to validate the inclusion of temporal considerations in universal and inclusive design.

Complexity Level

Complexity is a relative term often used to characterize something with many parts and an intricate arrangement, or one that requires a relatively high level of understanding or problem-solving process. Complexity seems to be the most apparent accessibility barrier for people with intellectual disabilities. Unfortunately, when asked to simplify instructions and communication, service providers often tend to comply by speaking louder or adopting a childish vocabulary and intonation. Although adults with intellectual disabilities benefit from simplified environment or information, the information should be age appropriate. In fact, publications by self-advocacy groups repeatedly request that people refrain from treating them as if they were children (Disabilityisnatural, 2007; Frawley, Bigby, & Forsyth, 2006).

The use of simple, or plain, language appropriate for adults with intellectual disabilities is not intuitive and, like any translation, should follow clear rules and protocols (Karreman, Van der Geest, & Buursink, 2007). Although the need to provide information in a way that can be understood by a person with intellectual disabilities is recognized in most accessibility legislation, standards, and regulations (ADA, 1990; Disability Discrimination Act, 1995; Israel Standard-1918, part 4, 2001), obligatory standards for easy language translation have yet to be developed. Growing awareness of complexity as an accessibility barrier led to the development of various guidelines for easy language translation (Table 1). Although these guides were developed for the translation of written information, some of the rules and recommendations provided can be useful for verbal communication as well.

Complexity, in terms of accessibility, is expressed not only in the level of verbal communication but in many other domains, such as layout of the physical environment, product-operating instructions, and procedures (both formal and informal) encountered in any service or program. Studies in various domains have recognized complexity level as an accessibility barrier for people with intellectual disabilities. These include studies of information and communication (Barker & Frazer, 2000; Karrema, Geest, & Buursink, 2007; Frawley, Bigby, & Forsyth, 2006), procedures and practices of service provision (Horowitz, Kerker, Owens, & Zigler, 2000; Iacono & Davis, 2003), and product design or environmental layout (Bryen, Carey, & Fridman, 2007; Carey, Fridman, & Bryen, 2005; Liu et al., 2006; MAPLE, 2003). The common conclusion from these studies was the call for simplicity as accommodation.

Literacy

The challenges of complexity level faced by people with intellectual disabilities are often interrelated with the challenges of illiteracy. Literacy levels among people with intellectual disabilities are relatively low. Surveys found that 87% of people with intellectual disabilities functioned at the lowest level of literacy skills as

Table 1 Representative Easy Language Guidelines

Examples of recommendation	Organization	Source
Keep sentences short (no more than 15 or 20 words) If you have to use a difficult word explain what it means Use full words and avoid abbreviations	Disability Rights Commission (DRC)	*Easy Read Guide* (DRC, 2006)
Use large print, a clear typeface, plenty of spacing Avoid jargon Use bullet points or fact boxes	Mencap	*Am I Making Myself Clear* (Mencap United Kingdom, 2000)
Use active rather than passive verbs Use simple punctuation Do not hyphenate words at the end of a line	Inclusion Europe	*Make It Simple* (Frehoff et al., 1998)

opposed to 21% of the general population (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993). Accordingly, many people with intellectual disabilities are excluded from aspects of information and communication in our predominantly literal society.

Accessibility means not only the right to enter and navigate a place but the right to use and enjoy a service and to receive information. By analogy, the experience of people with intellectual disabilities is sometimes similar to the case of a Western tourist in the Far East, where he/she cannot read the language and no English translation is available. This tourist may find it difficult to navigate, get information, or even order food. Studies exploring "way-finding" among people with intellectual disabilities have pointed strongly to inaccessible signage as a major barrier to independence and participation (Crown, 2006; Disability Rights Commission, 2003; Salmi, 2007; Salmi, Ginthner, & Guerin, 2004).

The significant accommodations that can be applied to address the literacy barrier of people with intellectual disabilities are (a) easy language translation, (b) signs and pictograms, and (c) alternative modalities (e.g., public address systems, auditory signs).

In the tourist examples above, literacy barriers are obvious and most countries try to accommodate for these needs. The literacy barrier is also obvious for minority groups, and, accordingly, translations are increasingly provided in government agencies as well as public and private services. The lack of such translations (e.g., from English to Spanish) is considered obvious discrimination. However, this is not always obvious for people with disabilities (Young & Quibell, 2000). A person with an intellectual disability who needs translation to simple language and/or graphic representations has a much harder time proving discrimination when such translation is not provided.

In addition to easy language translation, the use of graphic representation of information is very beneficial for people with intellectual disabilities (Salmi, Ginthner, & Guerin, 2004). Symbols, pictures, and pictograms can be excellent replacements for wordy signs or written verbal information. The development of a systematic, visual graphic communication system within the existing environment contributes to the well being, safety, and security of individuals with intellectual disabilities in unfamiliar, high-stress environments (Calori, 2007). Pictograms and all other graphic representation should include internationally agreed-on symbols or simple and intuitive graphic illustrations. The International Organization of Standards (ISO) provides detailed guidelines and methods for testing the comprehensibility of graphical symbols, to ensure that they are readily understood (ISO 9186:2001).

Alternative modalities can also be used to alleviate literacy demands. The use of alternative modalities, such as visual information provided also by auditory and tactile measures, is a well-developed accommodation for sensory disabilities

and supported by various standards and regulations (for a review, see Arditi & Brabyn, 2000). People with intellectual disabilities could benefit from alternative modality accommodations, such as public address systems or auditory signage. However, the effectiveness of these measures, as accommodations for people with intellectual disabilities, depends on the extent to which they conform to the appropriate pace and complexity criteria described.

The additional benefit of adoption of such accommodations is that, like many other universal design applications, such accommodations would probably be useful for most people, especially in high-stress situations (Calori, 2007).

Stigma

In addition to the three factors detailed above, stigma is perhaps the predominant barrier to accessibility. The ADA and other rights legislation promise accessibility, yet many barriers exist to realizing this promise for people with intellectual disabilities. Indeed, policymakers, legislators, service providers, and laypersons, more often than not, relate to accessibility for people with intellectual disabilities differently than they do needs of other populations. The legal right of people with intellectual disabilities to self-determination, independence, and access is not universally accepted, leading to disjuncture between their formal rights and the implementation of these rights. In other words, legislation offers rights, yet, in practice, people with intellectual disabilities cannot actively claim or implement their rights. They are often still treated as patients or people in need of protection and are expected to be escorted or supervised when accessing community programs and services. Although this might be appropriate for some, the range of functional abilities and support needs of people with intellectual disabilities is very wide (Luckasson et al., 2002), and many could function independently given appropriate accommodations.

From a legislation point of view, people with intellectual disabilities are often still thought of under the medical, rather than social, model of practice. Whereas legislation based on the medical model emphasizes benefits and service provision, legislation based on the social model emphasizes rights and social inclusion (Rimmerman & Herr, 2004). Not surprisingly, recent studies indicate a significant correlation between levels of self-determination and quality-of-life measures among people with intellectual disabilities living in the community

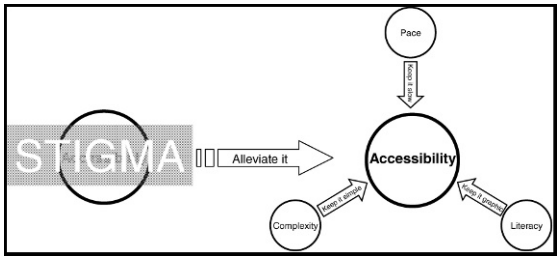

Figure 1 Conceptual model of accessibility considerations for people with intellectual disabilities. Provision of accessibility is primarily dependent on alleviating stigma. Detailed guidelines for dealing with pace, complexity, and literacy are provided in the text.

(Bonham et al., 2004; Lachapelle et al., 2005). Moreover, not only do higher levels of self-determination predict better transition from institutional to community settings (Wehmeyer, Garner, Yeager, Lawrence, & Davis, 2006) but they also correlate with levels of accessibility to health and education (Lee, Wehmeyer, Palmer, Soukup, & Little, 2008; Shigerman, Wehmeyer, Reese, & O'Hara, 2006). As more people with intellectual disabilities are moving from institutional to community settings, society faces the challenge of providing them not only with segregated services located within the community but also with reasonable accommodation that will enable them to use community services and facilities of their choice.

Training and education of service providers is often a key to the promotion of accessible services. Such training should strive to increase awareness of accessibility needs of people with intellectual disabilities and provide practical guidelines for the provision of accessible, equal, and respectful service to all.

Conclusions

The first step toward removing accessibility barriers for people with intellectual disabilities is reducing the stigma that prevents recognizing these individuals as a population with bonafide accessibility rights. After this is accomplished, creating accessible solutions for people with intellectual disabilities relies on the integrated consideration of pace, complexity, and literacy accommodations (see Figure 1). By acknowledging the rights of people with intellectual disabilities to receive not only health care, education, occupational support,

transportation, and leisure services but access to clinics and hospitals, schools, factories and offices, shopping centers, banks, stores, sports facilities, and numerous other sites in an equal, respectable, independent, and safe manner, we can foster an environment that embraces equal rights legislation, where people with intellectual disabilities can actively participate in society with maximum independence, privacy, and dignity.

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