Making both ends meet

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Abstract

The purpose of this article is to launch a new conceptual design tool in rehabilitation engineering, technology, and Disability Studies, useful both as guidance and help for people with disabilities in analyzing their own functional aids, and as inspiration and meta-guidelines for designers. It is non-discriminating and classification-free and differs from a mere classification system like the International Classification of Functioning (ICF). The origin of the tool is twofold: experiences of my own disability and of research in rehabilitation engineering.

Keywords: rehabilitation engineering, technology, disability, design, function

A. Introduction

Neither the medical nor the social model of disability is satisfactory for rehabilitation engineering and design. The medical model oversimplifies disability as an individual characteristic and directs attention towards individual adjustments and means. The social model, on the other hand, directs attention towards ideological and political analysis, not towards practical everyday solutions for experienced functioning.

Such an experienced functioning demands at least as thorough ideological considerations as do political analyses. The absence of an appropriate conceptual design model for rehabilitation engineering is a considerable hindrance for better functioning and better design of rehabilitation tools.

1. The Medical Model

The medical model, also called the deficit or individual model, has held and still holds a firm grip on society’s current conception of disability. This perception of disability places the problem with the individual and sees disability as a direct consequence of an impairment. However, there is a strong ideological opposition to the medicalization of disability in most disability organizations around the world (Basnett, 2001). Medicalization of disability meaning that the disability is seen as a direct consequence of the impairment and the medical condition of the body. People with disabilities view the medicalization of their everyday lives as a form of social oppression (Johnson & Woll, 2003). The professional use of medical knowledge has, in the case of people with impairments, expanded beyond the cure of the effects of illness. Batavia (1999) describes how this point of view considers people with disabilities "paternalistically as dependent patients rather than as self-directed individuals fully capable of autonomy." Far too many people in health care and society who make decisions of utmost importance for individuals (on such issues as functional assistance, for instance) have adopted the medical view of disabilities and consider clinical measuring, questioning, numbering and classifying to be the only yardsticks of choice. Almost all access to assistive or rehabilitative aids presupposes and calls for this kind of medical and "too-close" classification in the assessment and determination of various benefits (Oliver, 1990); it lacks a focus on the actual functions desired by the individual (Turner, 2001). It is alienating rather than supportive to the individual to be faced with a clinical analysis, a professional language of description and a lack of considerate interest for the functions most relevant in her/his own context.

2. The Social Model
People with disabilities are generally more inclined to adopt the social model approach. The Social Model of disability was formulated in the early 1980s, following the Union of the Physically Impaired Against Segregation (UPIAS) (1975) definition and separation of impairment and disability. The social model of disability originally referred to a rather materialistic view of the causes of disability, but has since been used in a number of contexts referring to the social creation of disability. Pfeiffer makes a distinction between the more materialistic U.K. social model and the social constructionist U.S. model based on Goffman’s “differentness” (Pfeiffer, 2002a & 2002b). Many more models or paradigms that can be said to originate from, or be versions of, the original social model are found in the academic research field of Disability Studies. The core message in most of them is that societal structures should be changed to accommodate people with disabilities, not individuals that should be changed to fit into a rigid environment and society. Disability is not a characteristic of the individual but rather the situated response to an inaccessible, inflexible and unadapted environment and society. This response is directed to a wide variety of people and excludes them because of their inability to conform to a societal concept of body normalcy. Disabling and discriminating attitudes are routinely produced and reproduced in social, political, and cultural practices in everyday life (Oliver, 1990; Barnes, Oliver & Barton, 2002; Barnes & Mercer, 2003; Albrecht, Seelman, & Bury, 2001).

Criticism of the social model has come from within the disability community. It has been criticized for not taking into account the physical body in its analysis of disabling factors. It has been depicted as too unbending in its concentration on structural societal factors and criticized for “disregarding the cultural and experiential aspects of disablism” (Barnes & Mercer, 2003). Barnes and Mercer describe three main strands of this criticism. The first is that the social model fails to recognize the physical and emotional problems that are associated with some impairments and that are disabling factors regardless of societal response. The second is that specific impairment groups are marginalized by some social model writings. The third criticism is that there is a failure to recognize that the experience of both impairment and disability can be very different for different groups of disabled people (Barnes & Mercer, 2003).

Much of this criticism can at first be seen as well-founded on the grounds that both individual and social factors influence everyday life for a person with an impairment. Still, the social model perspective, with its separation of impairment and disability, has undoubtedly yielded many political benefits and given a theoretical starting point for research, activism, and discussion. Furthermore, the body is not left out. Even one of the most “fundamentalist” social model advocates, Michael Oliver, acknowledges that:

This denial of the pain of impairment has not, in reality been a denial at all. Rather it has been a pragmatic attempt to identify and address issues that can be changed through collective action rather than medical or professional treatment (Oliver, 1996).

Still the influence of the social model has been limited and hindered by its stand-alone stance in relation to the fields of medicine, rehabilitation, and technology.

3. The Integrated Model and ICF

The integrated model of disability is an attempt to merge, or at least bring together, the medical and social perspectives (Seelman, 2003). This model allows for people with disabilities to have a number of different roles “including citizen and patient, among many others” (Seelman, 2003).

One of the operationalizations Seelman (2004) sees of the integrative model is the World Health Organization’s “International Classification of Functioning, Disability and Health” (ICF) (World Health Organization, 2001). ICF is probably the most well known existing framework used for analyzing the functioning of people with disabilities. The ICF has shifted, or at least broadened, the focus from its predecessor, ICIDH-1 (World Health Organization, 1980), which was strongly criticized by representatives of disability organizations (Pfeiffer, 1998; Hurst, 2000).

ICIDH-1 presented a predominantly medical and individual model for explaining disability, whereas ICF has sought to include environmental factors as well, along with activities and participation. The introduction of environmental and social response variables is a big step forward and very important, since ICF will be used by many health professionals and policy makers. The hope is that functionality shall not be assessed on its own, but be “qualified in relation to all other dimensions” (Hurst, 2003). But mixing these two paradigms does not come without problems. ICF still remains an instrument for measuring and classifying individuals on the level of impairment (Pfeiffer, 2000).
This also makes its use in an "integrative model" somewhat inappropriate or at least complicated both from an individual or social model perspective. Seelman (2003) finds that researchers should "be challenged to identify the relationships among the components" in ICF. This may be a good approach, but the relationships hardly lend themselves to description in numbered classification systems, since disability is a "complicated, multidimensional concept" (Altman, 2001). Measuring and classifying disability is fundamentally problematic with a risk for negative consequences, such as discrimination and labeling, as a result (Albrecht, 2002). The risk of creating a "we and they" that further widens the gap between professionals and people with disabilities is apparent. Barile finds that the classification in ICF "still centers the locus of the 'problem' in the individual's body," and that "the individualistic ascription of the 'victim approach' and the pathology are camouflaged but are still present" (Barile, 2003).

Rachel Hurst has pointed to the following problem with "too-close" classification:

There is no other group of individuals who have been subjected to this analysis of individual characteristics. Women and Indigenous people as discreet groups have been analyzed, but only in relation to their social, cultural and economic status. An in-depth classification of their individual characteristics has never been seen as necessary as an analysis of their status or for the provision of services or the implementation of policies to implement rights. (Hurst, 2000)

It can be noted that one aim of ICF is to provide a tool for international comparability of health information and in this respect; it may be successful. The aim of this article is not in any way to try to disprove the usability of ICF as a tool in some areas, but simply to make the observation that its method for classifying, measuring and numbering individuals is detrimental to its being used together with a social model perspective.

4. Technology as a Mediator

Not only societal and medical efforts need thoughtful models as a basis for their implementation. The same is true for rehabilitation engineering and design and their unquestionable potential to reduce function hindrances, to empower and enable.

The perspectives of Bruno Latour deserve to be illuminated. According to Latour (1991), technology is what makes a society durable. Technology and artifacts play an important role in how our predecessors continue to actively influence us and also how we influence each other. Nothing rules the future as recklessly as an infrastructure of old ideas. That is why it is primarily through changes in the way we think that the future is affected (Jönsson, B., 2001).

Technology and its artifacts (man-made constructions and objects) also exert an influence on the individual, both on how her/his thoughts are shaped and what she/he can and will do (and of course what she/he does not think or do). Håkan Jönsson sees artifacts as being imprinted with the goals, visions, and thoughts of their constructors. Artifacts are thus no neutral carriers of information (Jönsson, H., 2005). They affect how we relate to things and people around us, and how we learn about and perceive the world in which we live. From a socio-cultural perspective, we learn and develop by using cognitive resources that are incorporated in the artifacts as information, procedures and routines. Our way of thinking is guided and colored by the intellectual and physical tools we use (Säljö, 2000).

Technology and design can thus be seen as mediators of disability and can be used to create new and to consolidate old, disabling structures. But they also hold the power to break down existing disabling structures and create new function supports. Without a wheelchair I would not get anywhere, but my standard wheelchair does not give me much function in unspoiled nature or in an unadapted environment. Goggin and Newell give the example of how the wheelchair can be "theoretically regarded as an aid to mobility," but is an effective enabler only in a system where the environment is adapted to wheelchair use. They also write: "Without the necessary pavement, curbs, ramps, and funding of so-called access, the wheelchair as a system has different meanings and effects" (Goggin & Newell, 2003).

The wheelchair together with the environment is a system that can support or hinder function. From this starting point it is necessary for people with disabilities to problematize and influence the entire system of individual-oriented and individual-dependent technology in the space that exists between the individual and the environment. The body and the various technical artifacts around us make up a
system that enables or disables us to perform desired actions. Freund makes the following comment:

Space is also important because of the way its organization constructs bodies and offers bodily possibilities and constraints. The body is not simply a culturally constructed representation nor is it physically shaped like clay by social force, but it is experienced and ‘lived-in’ differently in various socio-material environments and material cultures (e.g., technologies) (Freund, 2001).

There is a difference if the wheelchair space in a movie theatre is located outside in the aisle or in the middle of the row. Regardless of the technical or design solutions, whether the wheelchair space occupies the best or worst situation in a theatre sends out different attitude signals. It is also important to note that these signals are received by all visitors to the movie theatre. The same goes for a lecture hall — if the podium is accessible with a wheelchair or not, if it is easily accessible with a permanent solution or if it is a provisional solution — all send messages about the attitude towards a lecturer in a wheelchair.

Technology is never just technology, the physical artifact. Technology is a manifestation of economical, political, social, and cultural concepts and individual wishes and ideas. For a designer or engineer or purchaser to be unaware of this can be potentially dangerous. Also, a naive belief that all technology is always for the better can be dangerous, especially for those extremely dependent on technological functioning.

This is why problematization of technology, its consequences, use and meaning is so important for Disability Studies. The “Guidelines for Disability Studies” published by The Society for Disability Studies (SDS, 2004) fails to directly acknowledge the importance of technology for the field. This is unfortunate, because technology and design are too important to be left only to the technicians and designers; it cannot be seen as being separate from other instances of the culture we live in. Technology and functional aids belong in the heart of Disability Studies.

B. My contribution: the FACE tool

Ten years of work in the field of rehabilitation engineering research with a focus on the lived disability have resulted in me developing "function" as a concept. Function is the main concept describing the outer course of events in the life of a human being (getting out of bed, going to the bathroom, taking a shower, getting dressed, having breakfast, reading the newspaper, taking the children to school, going to work, going to a meeting, reading and writing documents, learning, meeting people, being left alone, being a father, being a husband, going to a cinema, etc.). Function is analyzed by using three different factors: Attitude, Control, and Enabling.

1. Function

Most functions are possible to split up into a finite number of smaller functions. However, appropriate caution should be exercised so as not to use a more detailed level of description than is suited to the purpose of the person involved in the context of the function.

Functions are situated in a context, as are hindrances to functions. Functions are located in the space between the individual and his/her surrounding. Functions exist in concrete and well-defined situations but are not a property of the individual. Individuals neither can nor shall be classified with the function concept. Thomas (2002) makes a distinction between disability and what she calls "impairment effects." Impairment effects are, for example, that blind people (with today’s technology) are unable to drive a car safely or that someone like me in a wheelchair cannot play ice hockey for my local ice hockey team. This becomes a disability only if driving a car to work is a condition for obtaining paid employment, for instance (Barnes & Mercer, 2003), or if I wanted to try to pursue a carrier as a professional ice hockey player. According to the definition of function in this article, functions deal with the effects of impairment in order to reduce disabilities. The interest is in identifying and analyzing the situations where an impairment can lead to a disability and discovering how technology can affect this situation.

It is the function, as experienced by the individual in the environment in which technology has been introduced that is the measure of the function. Functions are thus assessed by how well they correspond to the desired action from the perspective of the individual and not relative to a preconceived norm. It is by long chains of functions that a day and a life are built. From the
A technological perspective used in this article, it is important to take the concept of function away from a mere mechanistic perspective and put it into a larger context with more variables.

A focus on functions could bring together the situated and relative perspective on disabilities found in the social model with the more individual and absolute perspective found in rehabilitation and rehabilitation engineering.

Sometimes there is a need to problematize space and to discuss functions from an environmental perspective rather than from an individual perspective. For example, to make sure a building is as accessible for as many people as possible, it can be of interest to discuss functions from a number of hypothetical cases. For each and every one of these cases a number of functions are enabled. Together these constitute the function opportunities of the environment. Affordance, according to Gibson (1979), is the relationship between a potential user and the physical artifacts in the environment affording possible actions in that environment. Function affordances are the potential functions available in any given environment.

An important factor to establish is that it is the person involved in the function, referred to as the owner of the function, who decides what a good function is. This is referred to as "ownership of the function."

There is a concept in the ICF called "functioning." This is not to be mistaken for the environmental and situated concept of function described above. Functioning in the ICF is defined as "an umbrella term for body functions, structures, activities, and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors." Body functions in the ICF definition are the "physiological functions of body systems (including psychological functions)."

The important difference is that function, as described in this article, never refers to bodily functions, but only to the realization of a desired action. Function cannot be assessed as an absolute measure, but only relative to the desired action, and situated in a context with appropriate function support. Functioning in the ICF includes body functions and structures; function as described here is firmly placed in the space between.

2. Function Support

An important concept to understand when discussing function is the concept of function support. Function support refers to what is needed to perform a function. It can refer to technology or to a person and it is made up of those requirements necessary to perform a function according to the wishes of the function owner. Function support always corresponds to a given function, but a function does not necessarily have dedicated function supports.

Function support consists of two main categories: technological and human. These two can be combined in a number of ways for the execution of a function. Human function support refers to when another person is a part of the execution. All other supports are classified as technological function supports, including the use of one's own body to perform a function. The difference between using human or technological function support is that the former has a will of its own. This can be a very concrete and tangible problem, something well known to all users of personal assistance. Technology has no will of its own, but is an extension of the user's will. In principle (and in this context) there is no difference between using a wrench or the hand to fasten a screw nut, but having an assistant do it does constitute a difference. There is no difference between walking and driving your own wheelchair, but if your personal assistant (PA) pushes your wheelchair it constitutes a difference, in terms of attitude, control, and enabling. One's own body is, in this context, considered to be more similar to the use of technical aids, as it is an extension of individual will.

It is an inevitable fact that the use of human function support in the form of personal assistance, for example, will constitute a filter to the world around, amplifying or reducing. Still, the use of human function support is often an unsurpassable system for enabling a function, since the possibilities for adjustment and adaptation to the environment are very high. One big problem with human function support is the loss of control. In a system with technological function support there is a high level of control, but normally it is less flexible, and thus has a lower enabling capacity.

The use of function support as a concept is to ensure that the function is looked upon as situated.
3. The disability "ACE"

Functions and function support can be analyzed by using the disability "ACE". It is made up of three different aspects of independence and disability eliminating/creating factors: enabling, control, and attitude. Each of the factors represents a different level of looking at functional assistance. Each level has its basis in my extensive experience as both researcher and developer in rehabilitation technology and as a user of functional aids.

Starting from the bottom, enabling is the traditional approach in rehabilitation technology. This concerns how the function supports are actually constructed and implemented, i.e. the technological solution. This is of course the basic level. The second factor is control, and this concerns the extent to which the user, the owner of the function, has the power and right to define and execute the function. This is the individual level. The top factor is attitude; this is the social response level. This concerns how the function is perceived by others and by oneself in the context where the function is used.

The ACE Assessment criteria

Attitude: To what extent is the function and the design of the function supports free from disablist and discriminating attitudes?

Control: To what extent does the individual have control of the development or choice of function support in the function?
To what extent does the individual have control of the execution of the function?
To what extent does the individual have control of the economy in the function?

Enabling: How well does the function correspond to the action desired by the individual?

To what extent does the desired function possible to perform (e.g., technology, economy, flexibility, etc.)?

The acronym FACE is made up of the first letters in the words "function, attitude, control" and "enabling." However, it also has a second meaning: the individual in need of function enhancement cannot be reduced to a series of numbers in a classification, but is an equal partner and truly the owner of the function, a face not a number.

The assessment is normative in the sense that a good function is one that gives an individual power over, or ownership of, the function and that strives to optimize the function according to the given criteria in accordance with the desired function of the individual.

A particular function can have different function supports depending on the extent of a person's impairment, interests, or wishes etc. Inversely, different function supports display a different FACE, so that the function support is more or less in accordance with the desired function. A disability results when a function support is missing, insufficient, or inadequate in a FACE analysis.

C. From Conceptual Design to Design of Artifacts and Infrastructure

Rehabilitation technology and engineering is the attempt to influence and affect with technology the interplay between a person and her/his environment in such a way that the person experiences an increase in functioning or functionality in this environment. Function is the product of all the experienced effects that the introduced technology has on the individual. Technology in itself is not rehabilitating but can be if it is used in such a function. This also means that all technology can be potentially rehabilitating, depending on the function it has for the individual who is using it.

Sometimes it can be hard to exactly realize a function according to a person's wishes. Functions like riding a rollercoaster or playing ice hockey may be impossible to realize because the physiology of a particular individual simply will not allow any enabling function supports. At this point it may be helpful to question, at the very outset, whether a solution should imitate fully the solution for a non-disabled person (the parrot method), have the same purpose but a different form (the chameleon method), or be completely different and only retain its fundamental characteristics, its very core (the poodle method) (Jönsson & Anderberg, 1999).

For example, in the case of the rollercoaster or ice hockey, what is the driving force? Is it a desire for an intellectual or physical challenge? Perhaps playing ice hockey on a computer is a better way to fulfill the wish for a challenge. Perhaps there is an altogether different activity that could provide the same challenge as a rollercoaster. Using the FACE tool can assist in finding the right function support.
Rehabilitation technology and engineering research must always begin and end with the individual. It is the function as it is experienced by the individual that is the measure and yardstick. It should, as well, always problematize who has the power over what technology should be developed and why, and what the problems are that need solving. To identify and place the ownership of a function means that the priority for defining is given to the person who is affected by the problem. Using FACE assures that all aspects of a function, not just the practical or technological, are evaluated and that invasion of privacy is avoided, since no body measurements are required.

The context in which rehabilitation technology and design practices are developed must be seen in the light of their cultural and social environment. The prevailing view of disability and people with disabilities affects how, which and why certain technology and function aids are developed and supported. There is also an inverse relationship: The view of disability and people with disabilities is also affected by the technology and function aids that are available and used by people with disabilities in the society. Using FACE assures that these attitudinal aspects are considered when designing functional aids.

Conclusion

Social model perspectives are needed in rehabilitating science and engineering, fundamental for control and self-determination for people with disabilities. They can be included without compromising the political benefits of the social model perspective if the focus is directed towards the space between the individual and his/her surroundings and towards the functional need and wishes rather than the mere functioning of the individual. The ability of FACE to eliminate the alienation of too-close methods of classifying is ready to be proven in use and in examples, and to be tested against the possibilities of the medical language when the goal is to achieve best possible function assistance, be it personal or technological.

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