Trends in Rehabilitation and Disability:

Transition from a Medical Model to an Integrative Model

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INTRODUCTION

The purpose of this lecture is to introduce and explore four models of disability: the traditional model, medical model, social model, and integrative model (Seelman, 2002). The four models often appear in sequential stages in the history of many industrialized countries. With the exception of the integrative model, the knowledge base for each model tends to exclude that of the other models. Throughout this presentation, the models are illustrated by corresponding policies, practices and research, using country-based examples mainly from the United States and, to a lesser extent, Japan. These models have implications for professional education and training of people with disabilities. Conclusions and recommendations will therefore address professional education and training people with disabilities as well as international and country-based policies, practices, research, and collaboration.

TRENDS

A number of international trends illustrate the importance of re-examining disability models that are operative in countries and international organizations. The first trend involves conflict between health professionals who identify with the medical model and people with disabilities who identify with the social model. Throughout the world, people with disabilities, who have formed a Disability Movement, are criticizing the medical model of disability and demanding greater participation in decision making (Basnett, 2001). The introduction of the World Health Organization's International Classification of Functioning, Disability and Health in 2001 suggests that a more integrative model may be emerging within the international community (World Health Organization, 2001). The integrative model adjusts for some of the criticisms of the other models and is already influential in country-based policy, practice, research and professional training <u>http://www.dpi.org/en/resources/topics/topics-convention.htm</u>.

The second trend involves technology. Increasingly, access to technology is associated with human rights as reflected in the Americans with Disabilities Act of 1990 (<u>http://usdog.gov/crt/ada/adahom1.htm</u>), the proposed United Nations Convention on the Rights of People with Disabilities (<u>http://www.dpi.org/en/resources/topics/topics-convention.htm</u>), and the World Summit on the Information Society (<u>http://www.itu.int/wsis;</u>

http://www.geneva2003.org). Policies, practices and research in universal design and design for all are examples of this trend. Human rights and technology are associated with demands to make mainstream systems and products, such as communication systems, transportation systems, and cell phones, accessible. However, accessibility features in mainstream systems and products may be regarded as "social add-ons"—not competitive in the global marketplace. Human rights and technology are also associated with policies, practices and research in special or assistive technology for individuals (e.g., wheelchairs or hearing aids). Interface problems for individuals with disabilities and technology and interfaces between specialized and mainstream technology have generated interest among researchers. The Trace Research and Development Center at the University of Wisconsin is one of a number of centers that conduct research on interfaces (http://trace.wisc.edu/world/gen_ud.html).

A third trend involves rehabilitation research itself. To justify payment, rehabilitation researchers across disciplines are called upon to show evidence of outcomes, efficacy, and effectiveness of assistive technology (Fuhrer, 2001). A fourth trend involves the struggles of social welfare program administrators to keep benefit programs solvent while serving growing numbers of people with disabilities, especially older people. Countries are adopting a mix of

social welfare, civil rights, and other policies to address disability issues (Van Oorscot & Hvinden, 2001; Zeitzer, 2002). Countries are struggling to contain costs of public welfare systems, but have often failed to adopt policies that may defer, lessen or negate the need for expensive institutionalization, such as accessible mainstream systems and products. Finally, the fifth trend is poverty—a barrier to the support of disability programs in developing countries where the majority of people with disabilities live. Many cultures continue to use a traditional model of disability. In the absence of scientific and health infrastructures, disability policy and practices may be based almost exclusively on culture and religion (Barnes & Mercer, 2003; Coleridge, 1993; Ingstad & Whyte, 1995).

MODELS OF DISABILITY

Four models of disability are explored in this section: the traditional model, medical model, social model, and integrative model. The following factors are considered for each model: a) knowledge base, b) roles, c) rules and relationships, d) temporal and spatial parameters, and e) bias. Corresponding policies, practices and research are identified for each model.

The Traditional Model

The traditional model is based on culturally and religiously-determined knowledge, views, and practices. Depending on cosmology, social organization and other factors, cultures show a broad range of perspectives which place people with disabilities on a continuum from human to nonhuman. For example, some cultures practice infanticide, rejecting the humanity of disabled infants. The roles people with disabilities may assume within a given culture range from participant to pariah (Barnes & Mercer, 2003; Ingstad & Whyte, 1995). When persons with disabilities are devalued, they may be perceived as demonic or unfortunate, and often take on the

role of an outcast (Coleridge, 1993). The bias of the traditional model is cultural relativity.

Objective, scientifically-based knowledge is not associated with this model.

Across cultures, people with disabilities have been valued differently. In his presidential address before the American Association of Physical Medicine and Rehabilitation, Thomas E. Strax, M.D. made the following observation:

From the beginning of time, humankind has wrestled with the paradox of what to do with people with disabilities. In ancient times, they were simply put to death. They were a burden on the tribe. In ancient Greece, there were 2 cities. Sparta removed the weak and the elderly for the good of the rest. In Athens, the warrior class protected the weak (Strax, 2003).

The Medical Model

The medical model is based on scientific views and practice, typically in the medical and health knowledge base. The "problem" is located within the body of the individual with a disability. The context of the medical model is the clinic or institution. Persons with disabilities assume the role of patient, a role that may be of either short-term or long-term duration depending on several factors, including the individuals' condition, policies related to institutionalization and community supports, and professional and social attitudes about disability. Authority lies with professionals. The bias of the model is the bio-medical perception of normalcy and the narrow band of legitimate knowledge, usually medical and health-related. Explanation of disability is reduced to the impairment level. The perspective of the person with a disability and social factors are not routinely within the knowledge base of the medical model.

Worst and Best Practices

In the West during the twentieth century, examples of worst and best medical research practices for people with disabilities can illustrate the strengths and weaknesses of the medical model. Worst practice examples can be drawn from most countries and regions.

- Willowbrook Experiments, U.S.: This study was designed to follow the natural progression of a disease—in this case viral hepatitis. Children with disabilities were intentionally infected with the virus and then studied during the progression of the disease. A particularly disturbing aspect of the research was that it was reviewed and approved by the New York State Departments of Mental Hygiene, Mental Health, the Armed Forces Epidemiological Board and the New York University School of Medicine, in addition to the Willowbrook School. Although parental consent was given, the consent was based upon the school's declaration that there was room for new students at the school only in the experimental unit (http://members.aol.com/bercar/caramain.htm).
- The Holocaust and People with Disabilities: There is evidence to show that people with disabilities were systematically exterminated and were the subjects of medical experiments during the World War II Nazi period in Germany (*Forgotten crimes: The holocaust and people with disabilities*, 2001).

Most countries and international organizations also have many examples of best practices

within the medical model. These include:

- Breakthroughs in biomedical and technological sciences and clinical applications that have saved lives and extended the lifespan of individuals with disabilities (National Institute on Disability and Rehabilitation Research, 1999)
- Research policy reform (<u>http://ohrp.osophs.dhhs.gov/irb/irb_guidebook.htm</u>)
- International Classification of Impairments, Disabilities and Handicaps (ICIDH) (International Classification of Impairments, Disabilities, and Handicaps, 1980)

After the Second World War, the international community adopted reforms and provided

guidelines for research. These policies include the Nuremberg Code of 1947, the United Nations

Universal Declaration of Human Rights of 1948, and the World Medical Association Declaration

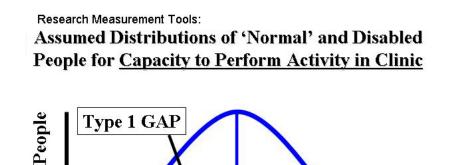
of Helsinki of 1964. Later, some countries began to adopt policies such as institutional review

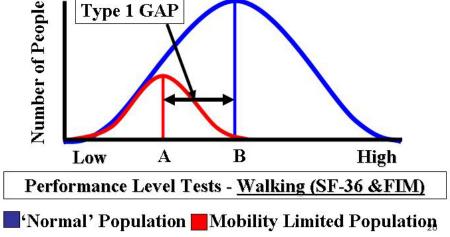
boards to protect research subjects.

The influential ICIDH, which identified the cause of disability within the individual, was adopted by many users including policy-makers (social security benefits, employment, occupational health), demographers, epidemiologists and statisticians (surveys), and healthplanners (utilization, resources). Even before the adoption of the ICIDH, health professionals created policy and designed surveys and utilization practices within the medical model. Throughout the twentieth century, countries adopted general social welfare and health policies (which usually included people with disabilities) as the first stage in a series of disability policies which would later include general and specialized education, employment, and accessibility policies for disabled people. Examples of social welfare and health policy include Japan's Social Insurance System developed beginning in 1922 and the Social Security Act adopted in the United States in 1935 (Miyatake, 2000).

Measurement Tools

Development and use of research measurement tools, such as the Functional Independence Measure (FIM), and concepts such as the normal curve reinforced the medical model. These tools were designed to measure impairment at the body level with the goal of curing the cause of the impairment—or at least minimizing performance difficulties. The test sites are usually clinics, rehabilitation centers or other controlled sites. The following is illustrative of measurement bias:





David Gray, 2002.

The distance walked is a key component of the health-related quality of life measure for the FIM. The measure focuses on the independent function of the person without contextual supports.

Professional Training

The knowledge base used to educate health professionals is rigorous and routinely limited to medicine and the health sciences. Therefore, health professionals may develop a view of disability that differs substantially from the reality of many disabled people. The following is a quotation from a medical doctor before he became disabled and afterward:

<I began> to examine his nervous system...felt a sense of horror come over me. You can't feel anything here on your shoulder? You can't move your legs? I next met this man in a spinal cord unit in 1985 as I was pushed to the computer next to him in occupational therapy. A few months earlier, I had severed my cervical spinal cord playing rugby and I was a quadriplegic—slightly more impaired than was my former patient. Now, 15 years after becoming disabled, I find myself completely at home with the concept of...being me. Now I know that my assessment of the potential quality of life of severely disabled people was clearly flawed (Basnett, 2001).

Disabled people may develop a view of health care that is very different from the one held by professionals. While professionals may view people with disabilities as patients, people with disabilities often accept their disabilities and move away from the patient role to resume life roles of worker, student and parent within the community.

Legacy of the Medical Model

The medical model is based on a narrow range of views and practices involving health and welfare. Research and research tools are useful for medical purposes but not as useful for social purposes, such as measuring accessibility and participation. Professional education and training, to the extent that it has not incorporated information about quality of life and accessibility, has resulted in a "dual perspective" situation. Therefore, there is a widening gap of understanding between professionals and patients who are at some stage of transformation and recovery (Gabard & Martin, 2003).

The Social Model

The social model is based on knowledge of the experience, views and practices of people with disabilities. The model locates the problem within society, rather than within the individual with a disability. From the perspective of the social model, disability is conceived more as diversity in function or the result of discrimination in policies, practices, research, training, and education. Individuals with disabilities are the authorities. They assume a range of roles—especially the advocate role—to pursue full expression of educational and employment opportunities and citizenship. Rules are determined within a framework of choice and independent living with strong support from organized disability communities. The biases of the social model include: limiting the causes of disability either exclusively or mainly to social and

Transition from Medical to Integrative Model

environmental policies and practices, or advancing perceptions of disability in mainly industrialized countries that emphasize individual rights rather than advancing broader economic rights that may reflect the needs of impoverished developing countries (Albrecht, Seelman, & Bury, 2001; Barnes & Mercer, 2003).

Policies and Practices

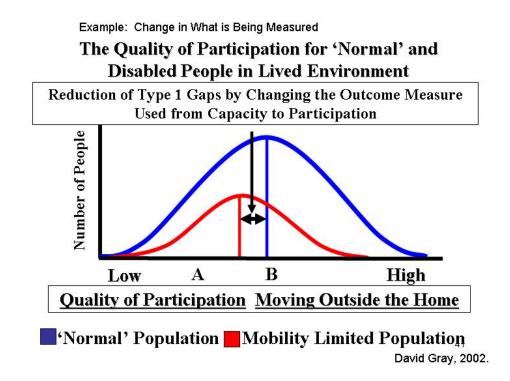
While retaining health and welfare policies of the first stage of disability policy, countries are in various stages of transition from the medical model to the social model. International organizations, some industrialized countries, and some developing countries have adopted second and third stage policies and practices of special laws in education, employment, civil rights, and accessibility. The United Nations began adopting disability human rights declarations in the 1970s in support of the principle of normalization of the lives of people with disabilities. Most countries in the second stage of disability policy have adopted special education and employment policies such as Japan's School Education Law of 1947 and the Individuals with Disabilities Education Act of 1975 in the U.S., which involved civil rights and mainstreaming of most children with disabilities {Statistical Abstracts, 2003; Education in Japan, 2001. Japan and the U.S. are among countries that have adopted special employment-related laws, such as Japan's Human Resources Development Promotion Law of 1969 and the U.S. Rehabilitation Act of 1973 which also involved civil rights (Employment and its Promotion of Disabled Persons in Japan: A Guide to Employment for Employers and Disabled Persons. 1999). Most of these laws provided services which were controlled by professionals. In the third stage, some countries began to move from special needs policies to a civil rights policy such as the Americans with Disabilities Act of 1990 in the United States. Others continued with a health, welfare, special education and special employment approach and often added policies to make buildings and information more accessible {Heyer, 2000;

http://www.dinf.ne.jp/doc/japanese/law/etc/z00003.htm;

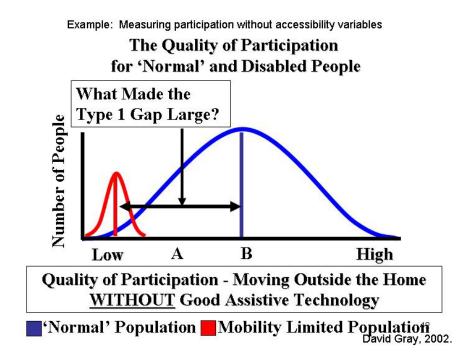
http://www.dinf.ne.jp/doc/japanese/law/etc/100002e/100002e01.htm).

Measurement Tools

The social model perspective incorporates research that examines problems of quality of life, user satisfaction, participation, and accessibility of various domains of the environment. The perspective also examines problems of participation of people with disabilities in the research process, including survey research. Researchers have explored methods to interview people with disabilities in survey research. Section 508 of the U.S. Rehabilitation Act as amended in 1998 may require federal electronic-based surveys to be accessible to people with disabilities, not only in the collection of survey data, but also in the analysis and reporting stages {Hendershot, 2003}. New research tools have emerged to measure quality of life and satisfaction, including the Quebec User Evaluation of Satisfaction with Assistive Technology and the Psychosocial Impact of Assistive Devices Scale (Cook & Hussey, 2002; Scherer, 2002). Researcher David Gray has been involved in the development of measures of the environment (grayda@msnotes.wustl.edu). The following are examples of his work:

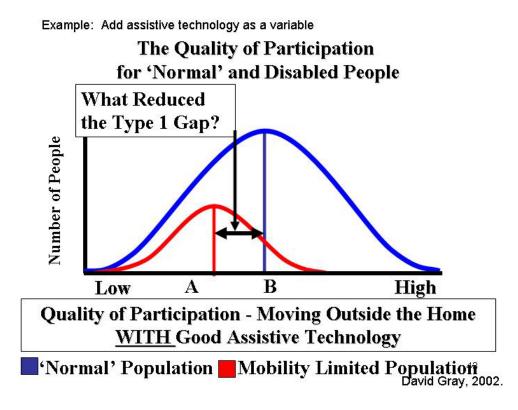


In this example, Gray changes the outcome measure from capacity to participation, which focuses on the individual's ability to function in his or her own environment. Although people with disabilities may score low in clinical tests of capacity, they may participate in many life activities including work, education, and family and community life.

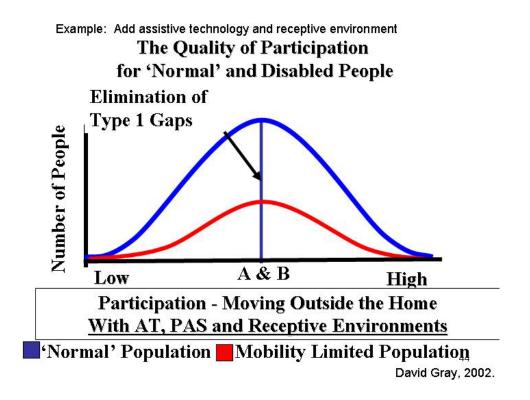


In this example, Gray shows the location on the normal curve of people with mobility

disabilities without good assistive technology.



In this example, Gray shows the location on the normal curve of people with disabilities with good assistive technology.



In the example above, Gray shows the location of people with disabilities on the normal curve when they have assistive technology, personal assistance and receptive environments.

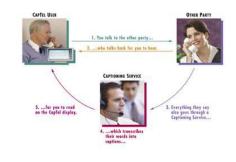
A number of the Rehabilitation Engineering Research Centers (RERC) of the National Institute on Disability and Research (NIDRR) have developed assistive technologies and universal design products that have increased participation of people with disabilities (http://www.naric.com/search/pd/). For example, the RERC on Universal Design and the Built Environment (http://www.ap.buffalo.edu) has developed a squat toilet and a visitable house as the following graphics show:



Research efforts have also worked toward the development of accessible communication devices. Title IV of the Americans with Disabilities Act charged the telephone companies with provision of interstate and intrastate telephone relay services that will provide deaf, hard-of-hearing and speech-impaired persons with telephone service functionally equivalent to service for hearing persons. The private sector has competed for contracts to develop and mange relay services. The CapTel System shown below is now in the testing stage.

(<u>http://www.ultratec.com/infoCapTel.html</u>) This system can be used by people with some degree of hearing loss because it works like a telephone but also displays every word the caller says during the conversation.

Telephone Relay Service for People Who Are Deaf and Hard of Hearing



http://www.ultratec.com/info/CapTel.html

48

Researchers have also modeled stages of change in organizations as they move towards

accessibility. The Center for Rehabilitation Sciences & Technology at the University of

Wisconsin at Milwaukee (http://www.uwm.edu/CHS/atoms/) developed a model called A3. The

A3 model conceptualizes stages in which organizations meet the needs of people with disabilities,

focusing on the physical and virtual environment, consumer products, services and systems. The

A3 Model includes three elements: advocacy, accommodation and accessibility. The advocacy

stage has the following characteristics:

- Minimal anticipation of needs
- Reactive to "complaints"
- Sometimes the person with the disability advocates
- Other times someone else advocates for the person with the disability
- People with disabilities receive a different "product" than people without disabilities

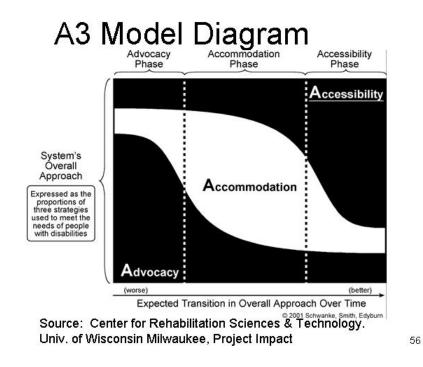
The next stage is accommodation. Characteristics of accommodation include the following:

- Anticipation of needs
- Prepared to meet needs
- "Complaints" are reduced as there is a system in place
- People with disabilities still receive a different "product" than people without disabilities
- Likely requires additional time, money, effort, etc.

The third stage is accommodation. Characteristics of accommodations are:

- Proactive
- Recognition that better design can reduce the need for individual accommodation
- Everybody receives the same "product"
- People with disabilities do not require additional time, money, effort, etc.

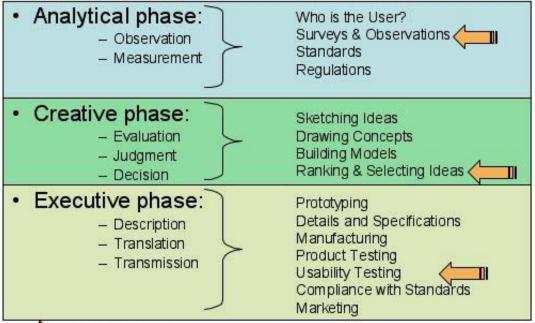
The stages are conceptualized in the following illustration:



Education and Training

The social model is based on a knowledge base of experiences of individuals with disabilities living in society. Adoption of the social model has led to demands to educate and train architects, designers, engineers and lawyers, as well as people with disabilities. Product design curricula may include the following considerations (see figures below):

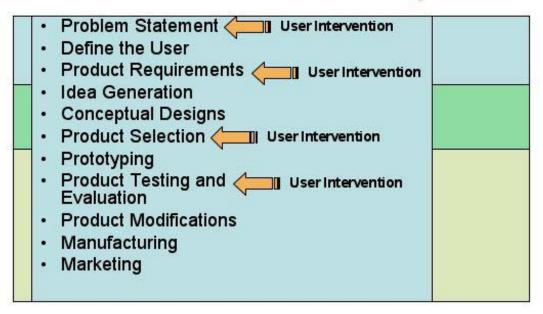
Universal Design Methodology



loser Intervention

[Van-Roosmalen: University of Pittsburgh, School of Health and Rehabilitation Science]

Universal Product Development



[Van-Roosmalen: University of Pittsburgh, School of Health and Rehabilitation Science]

Engineers have begun to receive clinical training. The University of Pittsburgh School of Health and Rehabilitation Sciences provides training in the Center for Assistive Technology and the University of Pittsburgh School of Law has launched a Disability Law curriculum. (http://www.shrs.pitt.edu/index2.html; http://www.cat.pitt.edu/; http://www.law.pitt.edu/about/index.html). A number of universities, including the University of

Pittsburgh, have added a Disability Studies curriculum (<u>http://www.uic.edu/orgs/sds/</u>). The best example of education and training within the social model is illustrated below:

Social Model: Example of Best Education and Training Practices, Social Integration



An example of community integration within the social model is illustrated below:

Japan: Example of Social Integration Attention Shifts to Group Homes for Intellectually Disabled Individuals







Source: Disability World. Issue 29. June-August, 2003. http://www.disabilityworld.org

60

The Integrative Model

The Integrative Model has a broad knowledge base ranging from medicine to literature which is informed by the experience of people with disabilities. The Integrative Model is "under construction". From the integrative perspective, individuals with disabilities have many roles, including citizen and patient, among many others. There are a number of evolving policies and practices that are representative of this model. Some of them are represented in the World Health Organization International Classification of Functioning, Disability and Health, the U.S. Institute of Medicine's *Enabling America: Assessing the Role of Rehabilitation Science and Engineering*, and the *NIDRR Long-Range Plan* (Brandt & Pope, 1997; National Institute on Disability and Rehabilitation Research, 1999; World Health Organization, 2001).

Policies and Practices

While retaining general health, welfare, special education, and employment policies and practices of the first and second stages, countries are in various stages of transition to a civil rights approach and related universality of design applications in systems and markets. International organizations, such as the World Health Organization, have developed a more universal approach to disability. The following interpretation of the ICF illustrates its universality and integrative characteristics (Schneider, 2001):

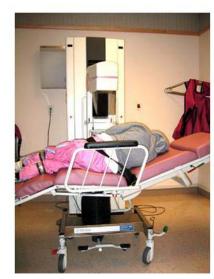
Universal Model Integrative Model Interactive Model Parity Inclusive Cultural applicability Operational Life span coverage	 not a minority model not merely medical or social not linear progressive not etiological causality contextual, environment & person not western concepts alone not theory driven alone not adult driven (children-elderly)
Operational Life span coverage	- <u>not</u> theory driven alone - not adult driven (children-elderly)
Human Functioning	- <u>not</u> merely disability

The components of the ICF encourage a broad and integrative classification. The three components of the ICF are body components, activities and participation, and environment. ICF researchers will be challenged to identify the relationships among the components.

The Disability Movement is pressing a number of international organizations for conventions and statements of principle committed to full integration of people with disabilities in society. The UN is being pressed to adopt a convention on the rights of people with disabilities (http://www.dpi.org/en/resources/topics/topics-convention.htm). The World Summit on the Information Society is being pressed to adopt a section on disability within the draft Declaration of Principles (http://www.dpi.org/en/resources/topics/topics/topics-convention.htm). Many of these initiatives have precedent in U.S. law. The Americans with Disabilities of 1990 (ADA) recognizes the full civil rights of people with disabilities (http://usdog.gov/crt/ada/adahom1.htm).

The ADA also provides assistive technology and accessibility of communications with important roles in the realization of rights and opportunities. The United States has regulated the communications industry to assure access. The original Communications Act of 1934 recognized universal access for all people in the United States. In 1996, the new Telecommunications Act was amended to include rules requiring telecommunications manufacturers and service providers to make their products and services accessible to people with disabilities, if readily achievable (http://www.access-board.gov/telecomm/html/telfinal.htm). The United States has also created market incentives to motivate industry to make its systems and products accessible (http://www.section508.gov/). As Section 508 of the Rehabilitation Act requires, the United States government constitutes a large market for accessible technology and employs the federal procurement system to purchase it (http://www.ittatc.org/laws/255.cfm). Section 508 requires access to electronic and information technology provided by the Federal government. The law applies to all federal agencies when they develop, procure, maintain or use electronic and information technology. Federal agencies must ensure that technology is accessible to employees and members of the public with disabilities to the extent it does not impose an "undue burden". Section 508 speaks to various means for disseminating information, including computers, software and electronic office equipment. It applies to, but is not solely focused on federal pages on the Internet or the World Wide Web. It does not yet apply to web pages of private industry.

Applications of technology within the integrative model appear below. The first example is a mammogram at Magee Women's Hospital in Pittsburgh made accessible for patients with disabilities:



Multi-purpose chair in reclined position, used for a mammogram



Magee continued

75

Other examples show President Clinton viewing an accessible voting kiosk and the CEO

of Microsoft viewing accessible equipment:

Research Applications: President Clinton Viewing Accessible Voting Machine at the White House 1999



66

Research Applications: the Marketplace and Microsoft President and CEO

"Microsoft applauds the government's efforts to lead the way in requiring accessible technology to be the standard and not the exception"

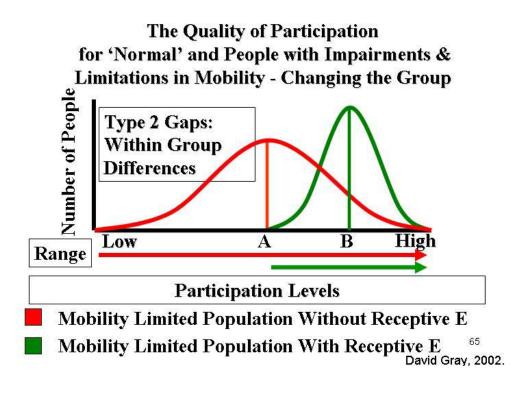


http://www.quadmedia.com/p41800pressrelease.htm

67

Measurement Tools and Principles

Disability is not inherent in measurement tools designed with the integrative model in mind. Psychological, social and environmental factors must be incorporated into assessments that are based on an integrative model. Assessment measures that are consistent with the integrative model assume a real world context of school, family, employment. Health service performance measures should be based on consumer outcomes. Some measures of disability may be disability specific in which case they may change the perception of the capability of the individual. David Gray illustrates this point below (grayda@msnotes.wustl.edu):



Researchers at the RERC at the University of Buffalo (http://www.ap.buffalo.edu) have

developed a prototype database on anthropometry of wheelchair users.



Research Example : Special Measures

Anthropometrics

> Overview

- Development of a prototype database on anthropometry of wheelchair users
- 2 Problems
 - Little information available
 - Information not readily usable
 - Different methods used in all existing studies
- Developing standardized approaches, collection of data, presentation of data for a large sample of wheelchair users



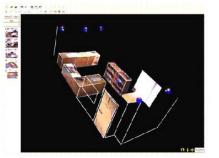
Researchers at the Department of Rehabilitation Sciences and Technology, School of

Health and Rehabilitation Sciences have developed a Virtual Reality Tele-Rehabilitation System

for Analyzing the Accessibility of the Physical Environment.

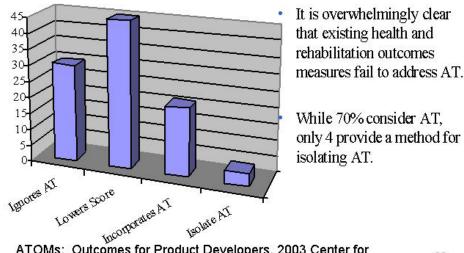
3. 3D modeling (continued)

 <u>To make 3D</u> models of physical environments of the wheelchair user's home from 2D photos.



The slide below shows the need for research in outcomes for assistive technology.

Applied Research Example of Future Research on Outcomes Field Scan 2 – Treatment of AT in Current/Emerging Health & Rehabilitation Outcome Measures



ATOMs: Outcomes for Product Developers, 2003 Center for Rehabilitation Sciences & Technology

83

Education and Training

The ICF has become a useful framework on which to base coursework for individuals across a wide number of fields, including the health professions, social work, psychology, and Disability Studies. Over thirty ICF-related courses have been identified in universities in the United States and Canada (<u>icf_clearinghouse@listserv.cdc.gov</u>). For example, the University of Pittsburgh Department of Occupational Therapy has adopted the ICF as the foundation for curriculum design.

CONCLUSIONS, OPPORTUNITIES AND CHALLENGES

In the international area, the following policy, research and practice opportunities and

challenges exist:

- Monitor UN Implementation of the Standard Rules and enact a UN Disability Human Rights Convention
- Incorporate a statement on accessibility for people with disabilities into the World Summit on the Information Society draft principles
- Support developing countries in provision of programs and participation for people with disabilities
- Develop the ICF measures for social and environmental factors so that assessment measures assume a real world context of school, family, employment
- Base health service performance on consumer outcomes
- Generate global marketplace incentives and standards to support universal design, usability and accessibility in product design and sale
- Add disability to surveys of health, income, employment and education

In addition to the above the domestic area provides the following opportunities and

challenges:

- Commit public and private research and development funding to technological inclusion of people with disabilities
- Promote technological inclusion by linking technology policy to civil rights
- Monitor research policies to protect people with disabilities in research conducted abroad with domestic research funding
- Create a government marketplace for usable and accessible systems and products
- In the practice area, the following opportunities and challenges exist:
- Promote science, technology and education and training opportunities for people with disabilities
- Integrate the perspective of people with disabilities and social and environmental factors into curricula

- Broaden the range of disciplines that address disability to include engineers, designers, lawyers
- Adopt the ICF as a framework to develop health-related professional education

In research, the following opportunities and challenges exist:

- Develop measures of social factors and environmental domains
- Develop accessible survey research process and questions about social behavior and environmental accessibility
- Develop evidence-based practice
- Develop assistive technology outcome measures

Opportunities for collaboration exist:

• Develop strategies based on the Tokushima Agreement between Japan, the United States, Australia and Europe

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