Disability and Rehabilitation in Developing Countries

Celia Pechak, PT, MPH, PhD(C)
Mary Thompson, PT, PhD
Texas Woman’s University
Dallas, Texas
2007

Prepared as part of an education project of the Global Health Education Consortium
Learning objectives

1. Describe the personal, social and economic consequences of disability in developing countries
2. Explain the importance of considering the cultural and social contexts of disability
3. Recognize the role that all health care providers play in caring for the growing number of persons with disability & in the prevention of disability
4. Discuss the complexities of implementing medical rehabilitation and community-based rehabilitation
Definition of disability

- World Health Organization’s definition of disability is found in the International Classification of Functioning, Disability and Health (ICF)
  - *Disability* serves as an umbrella term for *impairments, activity limitations or participation restrictions*
  - The ICF provides standardized language and framework

Photo credit: 2006 Pradeep Tewari, Courtesy of Photoshare
Factors influencing disability

• Despite WHO’s definition, defining disability is complex
• Each individual’s limitations may be affected to different degrees by any of the following:
  – Positive or negative societal attitudes about and treatment of persons with disabilities
  – Presence or absence of environmental barriers
  – Extent of support services
  – Positive or negative economic factors
  – Extent of employment opportunities
  – Presence or absence of legal protection
Global estimates of disability

- WHO estimates that over 650 million people live with disabilities worldwide, or 1 in 10 of the WORLD’S POPULATION

- Of those, 80% live in low-income countries with inadequate access to health & rehabilitation services

- Numbers are increasing, & are expected to continue to rise due to population growth, aging, & medical advances

Photo credit: 1989 Henrica A.F.M. Jansen, Courtesy of Photoshare
Common causes of disability

• Chronic conditions
  – Cardiovascular disease
  – Chronic respiratory conditions
• Injuries at home, work, on the road
• Injuries from violence & landmines
• Birth defects
• AIDS
• Malnutrition
• Mental illness

Photo credit: 2004 Ram Prasad Humagai, Courtesy of Photoshare
POVERTY & DISABILITY:

Poverty is associated with lack of access to prenatal care and regular healthcare, malnutrition, living in degraded environments, unsafe working conditions, and violence. In a developing country, a child with disability may not have access to an education. An adult with disability will have few opportunities for employment. In either case, a safety net will likely not exist to spare them from a life of poverty.
Disability effects on individual & family

- Social stigma
- Discrimination
- Marginalization
- Economic hardship/poverty

Photo credit: 2002 Jonathan Frerichs/Lutheran World Relief, Courtesy of Photoshare
Effect of disability on society

- Diminishes economic development
- Negative impact on social development
- Disability Adjusted Life Years (DALY) is the indicator used to quantify the burden of a particular disease from a population perspective
Cultural context of disability

- Disability must be considered within the context of the country’s culture and/or the individual’s subculture

- Culture will influence how people with disabilities are treated by family and society, and how the person with disability perceives his situation
Disability causes shame

A family in a rural developing country is ashamed of having a child with cerebral palsy who is unable to walk, speak, and is incontinent. The child has not been out of the house since he was 3 years old and the family keeps him hidden from the community. Local rehabilitation workers are unaware of the child’s existence.

MORAL MODEL OF DISABILITY: This case is a reflection of the moral model of disability, whereby disability is associated with sin and shame. While the oldest model of disability, it remains relevant in many cultures in developing countries and its negative influence upon persons with disability cannot be underestimated. For a more detailed description of the moral model of disability, see: Kaplan, D. (n.d.). The Definition of Disability. Retrieved July 21, 2007, from www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm#01
Cultural competence & rehabilitation

• Cultural competence:
  A set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enable that system, agency, or those professionals to work effectively in cross-cultural situations

• The process of cultural competence must be incorporated into the design and implementation of rehabilitation services.

• The impact of culture in the rehabilitation process should not be underestimated.
Culture & rehabilitation: A question for reflection

Reincarnation

If the individual believes he must suffer in this life for discretions in a past life, what is an effective way to approach rehabilitation?
Culture & rehabilitation: A question for reflection

Family-oriented culture

Some cultures do not value individual independence; rather, the role of the individual in the family is of utmost importance. In this case, instead of focusing on reaching functional independence, how can the rehabilitation team set goals with the client and family that reflect the client’s value system?
Disability rights

• Increasingly people with disabilities are organizing and advocating for full civil and human rights at local, national, and international levels.

• In December 2006, the United Nations General Assembly adopted the International Convention on the Rights of Persons with Disabilities.
  • mandates that countries ensure people with disabilities be granted equality, and freedom from discrimination.

Photo credit: 2007 Lee Mantini, Courtesy of Photoshare
Medical care & rehabilitation

- The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities stated that medical care and rehabilitation should be requirements for persons with disabilities to enjoy equal participation in their societies.
Disability & rehabilitation services in the shadows

• In the global public health arena, rehabilitation services have been overshadowed by more dramatic efforts, such as combating infectious diseases with immunizations

• Most medical schools and schools of public health around the world do not incorporate a disability and rehabilitation component in their curricula
Disability: an issue for all health care providers

• Given that 1 in 10 of the world’s population is disabled, the needs of the disabled must be addressed by all health care providers, not just rehabilitation providers

• Similarly, all health care providers play a role in injury and disability prevention
Notes on Preventing Disabilities:

Health care providers from developed and developing countries should participate in health promotion and model behaviors that help prevent disabilities. For example, seat belts are often not used in cars, or helmets on motorcycles or bicycles in developing countries. One physical therapist volunteer from Health Volunteers Overseas provided helmets to all staff in a rehabilitation department in Vietnam, and educated them about their roles in health promotion/injury prevention. As part of a Health Volunteers Overseas project to improve the care of patients with stroke in Vietnam, the volunteer physiatrist and physical therapist advised the rehabilitation team on how to enhance their prevention as well as treatment interventions. Subsequently, the rehabilitation team implemented a non-smoking policy in the rehabilitation department and initiated a smoking cessation program for patients.
The role of rehabilitation in the global health arena is expanding as persons with disabilities and other stakeholders are drawing attention to the rights and needs of the growing number of persons with disabilities.

Rehabilitation providers possess unique knowledge and skills to optimize the care of persons with disabilities.

For information about the unique knowledge and skills that rehabilitation professionals offer to persons with disabilities, see:

World Confederation for Physical Therapy: [www.wcpt.org](http://www.wcpt.org)
World Federation of Occupational Therapists: [www.wfot.org](http://www.wfot.org)
Medical rehabilitation

- Medical rehabilitation ideally includes:
  - Medical care
  - Rehabilitative nursing
  - Physical therapy
  - Occupational therapy
  - Speech therapy
  - Psychosocial therapy
  - Prosthetic and Orthotic services
  - Vocational rehabilitation
Reality of medical rehabilitation

• Adequate medical rehabilitation is woefully lacking in most developing countries

• When available, medical rehabilitation is usually found in the urban centers, inaccessible to many because of financial costs and/or geographical distance
Reality of medical rehabilitation

• Physicians with rehabilitation training are uncommon
• Physical therapists have widely variable levels of training and autonomy
• Occupational therapists are uncommon
• Speech therapists, rehabilitative nurses, and psychosocial personnel are rare
• Prosthetic and orthotic personnel availability and level of training varies
World Health Organization efforts: WHO Disability & Rehabilitation Team

- Develops normative tools, including guidelines and a global plan of action, to strengthen medical care and rehabilitation services

- Supports countries to integrate medical care and rehabilitation services into overall primary health care

- Facilitates the strengthening of specialized rehabilitation centers linking the services they offer to community-based rehabilitation
Complexities of capacity building

• Variable levels of human/educational/technological resources and infrastructure are available for training rehabilitation workers and delivering services

• Building and equipping medical rehabilitation institutions, and training professional rehabilitation personnel is not a realistic solution for all countries and settings
Complexities of capacity building

- Differing levels of education, scopes of practice, and practice patterns between rehabilitation professionals in developed countries and developing countries

- “Brain drain” – Rehabilitation professionals emigrate to developed countries to seek greater economic opportunities

**DIFFERING SCOPES OF PRACTICE & PRACTICE PATTERNS:** Physical therapists, occupational therapists, speech therapists, and nurses in developed countries are increasingly practicing with higher levels of education, greater independence, and broader scopes of practice. In the USA, for example, the predominant entry-level degree for a physical therapist is a clinical doctorate, and practice without physician referral is becoming more commonplace. Therefore, when therapists from developed countries are working to improve rehabilitation services in developing countries, a culture clash related to practice and professional status can occur. Complexities related to capacity building are magnified if all stakeholders cannot reach agreement as to what level of rehabilitation practitioner is appropriate for the culture and setting.
Complexities of capacity building

• Absence of, or variable, credentials and/or licensing

• Personnel without rehabilitation training may fill paid rehabilitation positions even when trained rehabilitation personnel are available

• Lack of paid positions even when trained rehabilitation personnel are available
Resources for improving medical rehabilitation

• International and national government-supported programs

• Collaboration between universities in developed and developing countries

• Non-governmental organizations
Non-Governmental Organizations Involved in Medical Rehabilitation:
Italian Association Amici dia Raoul Follereau (AIFO) -- www.aifo.it/english/index.htm
Handicap International -- www.handicap-international.org
Health Volunteers Overseas -- www.hvousa.org
International Committee of the Red Cross -- www.icrc.org
International Society for Prosthetics and Orthotics -- www.ispo.ws/index.php
Vietnam Veterans Foundation of America -- www.veteransforamerica.org/

Medical Rehabilitation Resources:

For an overview of the global health key players in general, see:
Global Health Players: Organizations Involved in International Health
www.globalhealth-ec.org/GHEC/Resources/GHplayers_resources.htm
Community-based rehabilitation

- Community-based rehabilitation (CBR) has been promoted by WHO and others since the 1970s as a strategy to meet the needs of people with disabilities in their own community.

- Institution-based care is neither readily available to most persons with disabilities, nor necessarily appropriate.
CBR workers

• CBR workers are trained to provide rehabilitation care to the persons with disabilities in their own homes and communities and advocate for their inclusion into the society

• Through training CBR workers, rehabilitation professionals are able to disseminate rehabilitation services wider and directly involve local communities
CBR: not just “home therapy”

• The concept of CBR extends far beyond providing “home therapy”

• CBR workers assist with “brokering” the persons with disability and families into society through networking and advocacy

• CBR requires the efforts of the persons with disabilities, their families, communities, and local service providers
Inclusion as the goal

- The ultimate goal of CBR is for the person with disability to gain full inclusion in his society.

- For inclusion to occur, the person with disability may require rehabilitation, but even more so, the community itself may need to change their own limited perceptions about and biases against persons with disability.

**WORKING TOWARDS INCLUSION:** Changing a community’s perception of what a person with disability is capable of is not a simple process. However, with time and the efforts of persons with disabilities and their advocates, change can occur.

Because the country’s school system would not allow children with disabilities, a physical therapist started a “school” in the pediatric department of the hospital in which she was volunteering in Bhutan. Having experienced the hospital school, one particular child with disability fought to gain admission to regular school. Eventually, through the example of the hospital school and the child's self-advocacy, the community recognized that children with disabilities could learn and wanted to learn, and the child was finally admitted to regular school. Now children with disabilities are routinely included in schools. See [www.unicef.org/bhutan/disable.htm](http://www.unicef.org/bhutan/disable.htm) for additional details.
Complexities of CBR

- Training and funding for CBR workers can be erratic
- CBR workers may be volunteers
- Workers may have many more responsibilities than just CBR, again leaving rehabilitation as a lower priority
Resources for CBR

• Many governmental and non-governmental organizations support and promote CBR

• Educational resources for training CBR workers
  – WHO CBR manual
  – Online training modules
  – Hesperian Foundation manuals
Assistive devices/technologies

• The provision of assistive technologies/devices is an important part of medical rehabilitation and CBR

• However, achieving full inclusion and participation of persons with disabilities into society goes well beyond providing appropriate assistive devices/technologies

• Provision of appropriate assistive technologies/devices can be deceptively complex
Assistive devices/technologies

Assistive devices/technologies improve the functional capacity of persons with disabilities to allow greater participation in activities of daily living, work, and play

- Prostheses (artificial arms/legs)
- Orthoses (braces)
- Wheelchairs
- Hearing aids
- Visual aids
- Computer software and hardware

Photo credit: 2002 Lydia Martin, Courtesy of Photoshare
Assistive devices/technologies

• Approximately 5-15% of persons with disabilities who would benefit from assistive devices/technologies have access to them in many low and middle income countries

• Health systems in developing countries do not typically manage the distribution of assistive devices and technologies

Photo credit: 2007 Jenny LM Hernandez/Handicap International Philippines, Courtesy of Photoshare
Barriers to obtaining assistive devices/technology locally

• Lack of adequately trained personnel to make and distribute

• Variable quality of locally produced products

• Excessively high cost

Photo credit: Kim Dunleavy
Role of non-governmental organizations

• Non-governmental organizations often coordinate the production and/or distribution of assistive devices/technologies

• Variable strategies employed
  – Shipping in the end-products & distributing to users
  – Establishing and/or supporting local production
    – Shipping in materials
    – Using locally-available materials
What is APPROPRIATE TECHNOLOGY?

- APPROPRIATE TECHNOLOGY
  - Is the technology truly suitable to the individual & his environment?
  - Can the technology be adequately maintained?
  - Can the technology be adequately repaired?

Photo credit: 2005 Peter Verbiscar-Brown, Courtesy of Photoshare
Is the technology SUSTAINABLE?

SUSTAINABILITY
– Can local production continue without imported materials?
– Can local production continue once external funding ends?
– Is training adequate to support ongoing production?
– Can persons with disabilities afford to purchase products?
No easy solutions: A case for reflection

Well-meaning individuals from non-governmental organization A arrived in developing country B and noted that many people with disabilities had no wheelchairs. They organized a large campaign to gather used wheelchairs in developed country C, and shipped them to developing country B for free distribution.

What could possibly be harmful with this seemingly simple solution?
No easy solutions: A case for reflection

Non-governmental organization A did not realize that a small wheelchair production company run by people with disabilities existed in developing country B. Because the wheelchairs from non-governmental organization A were free, the wheelchair production company lost significant business, creating economic harm for the people with disabilities working there.

Could there have been better strategies for non-governmental organization A to help in this case the local people without causing harm?

Perhaps shipping donated wheelchairs is sometimes a reasonable short-term solution. However, understanding the big picture locally and exploring capacity building is critical for long-term change.
Addressing key issues for wheelchairs

Standards for the provision of wheelchair services in developing countries, including guidelines on the development, production and distribution of wheelchairs, are expected in 2007 from the World Health Organization.

Photo credit: 2002 Lydia Martin, Courtesy of Photoshare
Prosthetics and orthotics

- Provision of prosthetics and orthotics is even more complex
- Requires specialized training to assess, fabricate & fit
- Ongoing maintenance is required
- New prosthetic or orthotic is required as individual grows or physical condition significantly changes

Photo Credit: Kim Dunleavy
Future of rehabilitation in developing countries

• Rehabilitation’s role in global health needs to grow as the number of people with disabilities continues to increase worldwide

• Increased collaboration amongst rehabilitation professionals in developed and developing countries is essential to implement appropriate and sustainable rehabilitative services

• Information exchange, networking, and training opportunities are expanding with globalization trends and Internet availability, providing opportunities for increased collaboration amongst developed and developing countries to improve rehabilitation services
Quiz introduction

• Now we invite you to take the module quiz and test your recent learning with 10 questions. Note your answers on a separate and then compare them with the slides that follow the quiz.
• After completing your quiz, come back for the summary of this module presentation.
1. Global estimates of disability are that:

A 1 in 5 of all people are disabled  
B 1 in 10 of all people are disabled  
C 1 in 25 of all people are disabled  
D 1 in 50 of all people are disabled

2. Disability prevalence is expected to:

A Decrease  
B Increase  
C Remain stable
3. According to WHO, disability is an umbrella term for impairments, activity limitations or participation restrictions.

A TRUE
B FALSE

4. Disability should be viewed within the context of the country’s culture and the individual’s subculture.

A TRUE
B FALSE
5. Whose role is it to address the health needs of the persons with disability and advocate for their full inclusion into society?

A All health care
B Community health workers
C Community health workers and the medical rehabilitation team
D Medical rehabilitation team

6. The United Nations and the WHO Disability and Rehabilitation team promote the building of medical rehabilitation institutions and the training of rehabilitation professionals as the best solution to address the increasing prevalence of disability globally.

A TRUE
B FALSE
7. The ultimate goal of community-based rehabilitation (CBR) is to:

A. Save the person with disability the expense and time of attending therapy in rehabilitation institutions
B. Fully include the person with disability into society
C. Obtain the most appropriate assistive devices/technologies for the person with disability
D. Train the family to provide the physical therapy interventions in the home

8. Assistive devices/technologies are available to approximately _____ of the persons with disabilities who would benefit from them in many low and middle income countries.

A. 5-15%
B. 25-50%
C. 60-75%
D. 85-100%
9. The question of whether an assistive device/technology has been designed to meet the needs of an individual in his own environment is related to which key issue:

A  Affordability  
B  Appropriate technology  
C  Cultural competence  
D  Sustainability

10. The question of whether an assistive device/technology can be continued to be produced with locally available materials and/or without external funding is related to which key issue:

A  Affordability  
B  Appropriate technology  
C  Cultural competence  
D  Sustainability
Now check your answers against those in the next few slides
1. Global estimates of disability are that:

A 1 in 5 of all people are disabled
B 1 in 10 of all people are disabled - Correct - WHO estimates that over 650 million people in the world are disabled, or 1 in 10.
C 1 in 25 of all people are disabled
D 1 in 50 of all people are disabled

2. Disability prevalence is expected to:

A Decrease
B Increase - Correct - Disability prevalence is expected to continue to rise with population growth, aging, increase in people living with chronic conditions, amongst other factors.
C Remain stable
3. According to WHO, disability is an umbrella term for impairments, activity limitations or participation restrictions.

A TRUE - Correct -- Despite the relative simplicity of WHO’s definition, defining disability is complex. If you have not already, see the following for a discussion on the complexities inherent in defining disability: Kaplan, D. (n.d.). The Definition of Disability.  ww.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm#01

B FALSE

4. Disability should be viewed within the context of the country’s culture and the individual’s subculture.

A TRUE -- Correct -- Culture must be considered when addressing issues related to disability, including the design and implementation of rehabilitation services.

B FALSE
5. Whose role is it to address the health needs of the persons with disability and advocate for their full inclusion into society?

A All health care providers -- Correct -- While rehabilitation providers possess unique knowledge and skills to optimize the care of persons with disabilities, all health care providers should be prepared to address the broad needs of persons with disabilities.

B Community health workers

C Community health workers and the medical rehabilitation team

D Medical rehabilitation team

6. The United Nations and the WHO Disability and Rehabilitation team promote the building of medical rehabilitation institutions and the training of rehabilitation professionals as the best solution to address the increasing prevalence of disability globally.

A TRUE

B FALSE -- Correct -- While medical rehabilitation is an important component of rehabilitation, institution-based care is not a realistic solution for all persons with disabilities in developing countries nor does it address the broader issues of the social context of disability.
7. The ultimate goal of community-based rehabilitation (CBR) is to:

A  Save the person with disability the expense and time of attending therapy in rehabilitation institutions
B  Fully include the person with disability into society – Correct - The ultimate goal of CBR is for the person with disability to gain full inclusion into his society. While rehabilitation of the individual’s impairments is one facet of CBR, CBR requires the efforts of the persons with disabilities, their families, communities, and local service providers to advocate for the person with disability’s full participation in his society.
C  Obtain the most appropriate assistive devices/technologies for the person with disability
D  Train the family to provide the physical therapy interventions in the home

8. Assistive devices/technologies are available to approximately _____ of the persons with disabilities who would benefit from them in many low and middle income countries.

A  5-15% - Correct - Only approximately 5-15% of persons with disabilities who would benefit from assistive devices/technologies have access to them in low to middle income countries. Most health systems in developing countries do not manage the distribution of assistive devices/technologies, and the provision by others is deceptively complex
B  25-50%
C  60-75%
D  85-100%
9. The question of whether an assistive device/technology has been designed to meet the needs of an individual in his own environment is related to which key issue:

A  Affordability
B  Appropriate technology -- Correct -- Appropriate technology means that the technology is truly suitable to the individual and his environment, and that the technology can be adequately maintained and repaired.
C  Cultural competence
D  Sustainability

10. The question of whether an assistive device/technology can be continued to be produced with locally available materials and/or without external funding is related to which key issue:

A  Affordability
B  Appropriate technology
C  Cultural competence
D  Sustainability -- Correct -- Sustainability refers to the concept that technology production can continue with locally available materials and without external funding. In addition, adequate local manpower and skills must be available to support ongoing production, and persons with disabilities must be able to afford the products.
Summary

- Disability must be viewed within cultural and social contexts
- The increasing population of the disabled and their unmet needs should be the concern of all health care providers
- Providing effective rehabilitation will require the collaboration of stakeholders, including the persons with disabilities, in developing and developed countries
- Individual health care providers can contribute to the solution through networking, collaboration, and communication of available resources
Credits

Celia Pechak, PT, MPH, PhD(C)
Texas Woman’s University & Health Volunteers Overseas
Dallas, Texas
pechak@tyler.net

Mary Thompson, PT, PhD
Texas Woman’s University
Dallas, Texas
Acknowledgements

The authors would like to acknowledge the kind assistance of the following reviewers whose input greatly enhanced the quality of the content:

**Shaun Cleaver, PT, MSc**
International Health Division, Canadian Physiotherapy Association

**Sharon DeMuth, DPT**
University of Southern California & Health Volunteers Overseas

**Kim Dunleavy, PT, PhD(C)**
Wayne State University & Health Volunteers Overseas

**Nancy Gell, PT, MPH**
University of Michigan & Health Volunteers Overseas

To suggest improvements for future revisions, please contact Celia Pechak at pechak@tyler.net
The Global Health Education Consortium gratefully acknowledges the support provided for developing these teaching modules from:

*Margaret Kendrick Blodgett Foundation*
*The Josiah Macy, Jr. Foundation*
*Arnold P. Gold Foundation*

This work is licensed under a [Creative Commons Attribution-Noncommercial-No Derivative Works 3.0 United States License](http://creativecommons.org/licenses/by-nc-nd/3.0/).