

# Rights, Rehabilitation, and Disability: ICF

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# Societal Perspective, Disability Perspective

- UN documents, conventions, and actions are needed because individuals living with disabilities are often marginalized
- While we here may believe we are “the choir”, we all need periodic and systematic reminding of how habilitation/rehabilitation, disability and rights are intertwined
- The WHO ICF framework balances and includes these perspectives—rehab, disability, and rights.

# DEFINITIONS

- **RIGHTS**—something due persons by virtue of law or nature (in disability, equalization of opportunity to participate in society)
- **HABILITATION/REHABILITATION**—the process and system through which persons move toward the goal of gaining, restoring or maintaining function
- **DISABILITY**—an experience that all people may well have, in which function is limited and during which environmental characteristics are highlighted

## ICF codes

- d940 Human rights- enjoying all nationally and internationally recognized rights accorded to people by nature of their humanity alone.
- e595 Political services, systems and policies.

# Commonalities: Rights and Rehabilitation in the ICF

- Respect for the person
- Espouses empowerment rather than charity
- Interaction with the environment—identify barriers and facilitators; use on behalf of person(s)
- Outcome for both is increased participation of persons with disabling conditions
- Ignorance of either undermines the other—the various characteristics should complement another—conceptually and in practice.
- ICF creates a common language and framework

# INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH: THE BALANCE

- MEDICAL MODEL & SOCIAL MODEL
- REHABILITATION & DISABILITY
- CLINICAL & PUBLIC HEALTH
- TREATMENT & PREVENTION
- INDIVIDUAL TX & ENVIRONMENTAL  
CHANGE

# UN STANDARD RULES— Preconditions & Areas: rules 1-12

- **PRECONDITIONS FOR EQUAL PARTICIPATION**

- AWARENESS RAISING
- **MEDICAL CARE**
- **REHABILITATION SERVICES**
  - Activity LIMITATIONS
  - Participation RESTRICTIONS
- **SUPPORT SERVICES—**
  - ASSISTIVE DEVICES
  - SERVICING DME
  - PERSONAL ASSISTANCE

- **TARGET AREAS FOR EQUAL PARTICIPATION**

- FAMILY LIFE/PERSONAL INTEGRITY
- ACCESSIBILITY
  - BARRIER FREE
  - TRANSPORT
  - COMMUNICATION
  - HOUSING
- SOCIAL SECURITY— INCOME MAINTENANCE
- EMPLOYMENT
- SPORT & RECREATION
- CULTURE
- RELIGION

# Implications

- **PRECONDITIONS FOR EQUAL PARTICIPATION**
  - Medical care
  - Rehabilitation
  - Support services
- Already limits to each precondition
- How do we optimize them?

# Assessment of Health & Functioning

- **Diagnosis--ICD**

*(Disease, Disorder, Injury etc)*

- *Disease process & etiology (Signs, symptoms & findings)*

- **Functioning & Disability--ICF**

- *Body Structures and Functions (mental, sensory, cardiovascular, digestive, reproductive....)*
- *Activities/ Participation (communication, self care, learning, work, school, social, leisure, civic)*
- *Environmental factors (physical and built, attitudes, systems/policies)*

# ICF, Rehab, and Disability Rights

- **ACTIVITIES** domains allow identification of individual's limitations in personal function—learning, communication, mobility, self-care...
- **PARTICIPATION** domains allow focus on the outcomes of the UN rights—e.g. work, school, friends, leisure/play.....
- **ENVIRONMENTAL** factors allow systematic identification of barriers and facilitators in a person's neighborhood, community, state, and/or nation—physical and built, attitudes, policies, systems

# “Maximizing Abilities through Science and Compassion”

- **Abilities**

- Assessment of impairments, activity limitations, and societal restrictions
- Assessment of environmental factors—barriers and facilitators
- Assessment of assistive technology needs
- Assessment of additional assistance—personal and otherwise
- Interventions that address the person and family needs

# Maximizing Abilities through Science and Compassion

- **Science**
  - Evidence-based interventions
  - Outcomes, emphasizing Participation
- **Compassion**
  - Rights
  - Values

# ICF AND PHYSIATRY: a study

- Kukafka, et al., Columbia University, NYC
- Presence of functional information in PM&R discharge notes—
- Used MedLEE computer processing to detect functional status and translate into ICF codes

# Environment, Rehab, and Disability

- Disconcerting truism—Many/most people with disabling conditions attribute their decreased societal participation to the limitations associated with their impairment, not to environmental barriers.
- Adage: “...grant us the serenity to accept the things we cannot change, courage to change the things we can, and wisdom to know the difference.” How much change in participation in society is possible?
- Many in the disability community suggest nothing in the environment is unchangeable—save the weather.
- Is there a different standard for environmental change in rehab settings than in the community?

# Environment, Rehab, and Disability

- The issue is helping folks understand the importance of environments—including medical, rehabilitation, social, vocational....
- We must balance rehab and disability, individual and societal, treatment and prevention, even in the context of our own day-to-day work.
- Policy and research needs to keep clinical relevance in mind, and clinical and program need to be aware of and work toward policies that help.

# What would it be like if...

- The respect we espouse were implemented in the settings in which we move, the places we work?
- How is that respect now shown in medical care, rehabilitation, support services?
- How is respect seen in the research we do, the programs we plan and implement, the services we provide, the policies we support?

# Our Tasks

- Responsibility of the rehabilitation and disability professional communities
  - Communicate more clearly among ourselves—practitioners, scientists, program leaders, and policy makers--about overlapping issues. ICF allows us the common language. ICF is a second language for all.
  - Balance our own perspective with that of others, beyond our discipline, guild, or work setting

# Our Tasks

- Acknowledge and integrate environmental issues into our assessments, interventions, and education of those we serve—at the level of body, person, and society. ICF provides the framework across dimensions
- Educate ourselves about environmental barriers at the physical, attitudinal, and policy/system levels.

# The rights of children

- "A century that began with children having virtually no rights is ending with children having the most powerful legal instrument that not only recognizes but protects their human rights".

(Carol Bellamy, UNICEF Executive Director)

# UN Convention on the rights of the child

- Integrity a person: Articles 1-3
- Inherent right to life/survival: Article 6
- Identity Articles 7-8
- Family environment: Article 9, 18
- Right to be heard Article 12,13
- Protection from exploitation: Articles 19,32,34
- Protection in institutional care: Article 20, 25
- Education Article 22
- Highest allowable health Article 24

# Vulnerability of children

In every society, children's inferior role, dependency on others and limited ability to advocate for themselves render them uniquely vulnerable to deprivation of their rights:

- Poverty, malnutrition
- Exposure to infectious disease (AIDS, malaria...)
- Child labor
- Restricted access to education; particularly girls
- Exploitation
- Victims of hostilities, loss of family

# Vulnerability and deprivation of rights of children

Right	Deprivation
Integrity as person	Lack of services, supports
Right to life/ survival	Morbidity, mortality
Identity	No birth certificate
Education	Lack of schooling for girls
Highest allowable health	Lack of immunization
Family environment	AIDS orphans
Protection in institutional care	Institutional deprivation
Protection from exploitation	Child labor; child pornography

# Deprivation of rights of children

(UNICEF, 2002)

Deprivation of right	Sub-Saharan Africa	South Asia	East Asia Pacific	Other
Survival; deaths <5yrs	40%	34%	13%	13%
Nutrition: malnourished	52%	21%	18%	13%
Education: not in primary school	36%	38%	7%	19%
Health: not immunised-DPT	34%	41%	14%	12%
Child labor <9yrs; 21%				
10-14 yrs; 38%				

# Vulnerability of children with disabilities

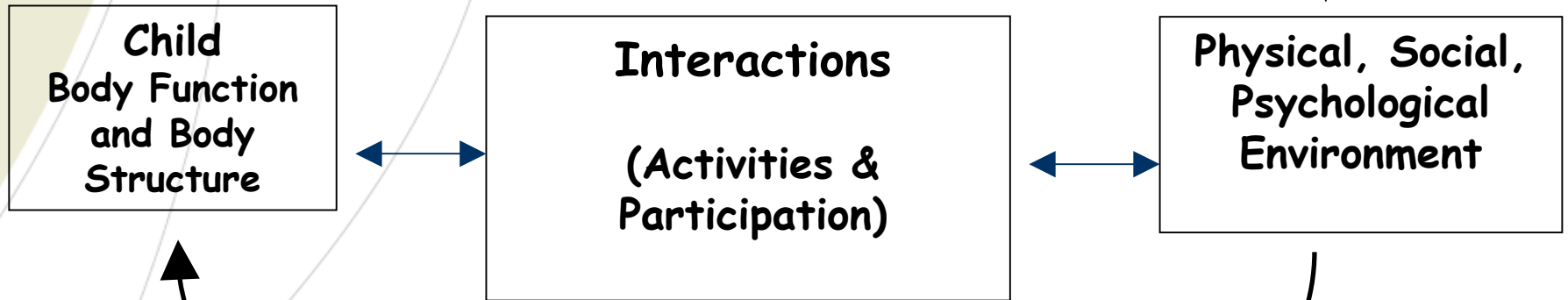
- Vulnerability is significantly increased in children with disabilities whose heightened dependence on others and need for support exacerbates their inferior role.
- Restricted access or opportunity > Schooling, health care, prevocational training
- Discrimination > Exclusion, social isolation, lack of friends
- Neglect > Institutionalization
- Physical/verbal abuse > Teasing, bullying, physical and sexual assault

# Defining disability and the deprivation of the rights

- **Rights-** equality of access to physical, social and psychological environments
- **Disability=** experienced or perceived limitations in child-environment interactions
- **Deprivation=** Constraint, limitation or barrier in child's **access to/interaction with** physical, social or psychological environment
- Principles of **accessibility and equality of opportunity** consistent with proposed International Convention on the Rights of Persons with Disabilities

# Modeling Child-Environment Interaction

*Acts upon; Reacts to*



*Source of Stimulation*

*Source of Feedback*

# Dimensions of deprivation of the rights of the child

- Constraints, limitations or barriers to child's encounters with environments in terms of:
- **Availability**- lack of essential, expected elements
- **Access**- inaccessible in space, time, form
- **Affordability**- time, energy or monetary cost
- **Accommodation**- no alternate forms for use
- **Acceptance**- limited tolerance of variation of appearance, demeanor, behavior

# Deprivation of the rights of children with disabilities

Dimension of constraint or limitation	Evidence
Availability	Malnutrition, medication
Access	Exclusion,
Accommodation	Lack of assistive technology
Affordability	Specialized care, supports
Acceptance	Discrimination, segregation

# Vulnerability and deprivation of children with disabilities

- Prior to 1970's children with disabilities did not have a right to education in many western countries and this right is still not realized in a number of developing countries
- Children and their families have difficulties obtaining resources, support and access to health insurance and providers
- Recent history of western countries reveals that only a few decades ago children with disabilities were assigned to lifetime of institutionalization
- This situation tragically still exists today in many countries of the world

# Vulnerability and deprivation of children with disabilities

- Heightened vulnerability of children in less economically developed countries
- Contemporary Russia as a case example: Medical providers encourage institutional placement of infants/young children who are "slow in development"
  - At 4 years of age, diagnostic decision is made
  - If judged "educable", placed in children's home with access to education
  - If judged not "educable", lifetime institutionalization, abuse, neglect...
  - (Rosenthal et al, 1999)

# Vulnerability and deprivation of children with disabilities

- A Russian health official describes the 4 - year evaluation as " a catastrophe for the child"
- Human Rights Watch describes it as "the point of no return" and concludes that..
- "after 4 years of collective care and individual deprivation, an alarming number of the children end up victims of the self-fulfilling prophecy of mental retardation"

# Rights of children with disabilities

- " Human rights are human only if they refer to everyone" (Grunewald, 2003).
- What are the human rights extended to children with disabilities?

# UN Convention on the Rights of the Child: Article 23, Par. 1

- "...a mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promotes self reliance and facilitates the child's active participation in the community"

# UN Convention on the Rights of the Child: Article 23, Par. 2

- "... right of the disabled child to special care and ...assistance ...appropriate to the child's condition and to the circumstances of the parents or others caring for the child".

# UN Convention on the Rights of the Child: Article 23, Par. 3

- "...assistance ...shall be provide free of charge, whenever possible, taking into account the financial resources of ..parents or others caring for the child, and..."

# UN Convention on the Rights of the Child: Article 23, Par. 3 cont'd

- "...child has effective access to and receives...education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities ...conducive to ...achieving the fullest possible social integration and individual development, including... cultural and spiritual development".

# UN Convention on the Rights of the Child: Article 23, Par. 4

- “....promote, ....exchange of appropriate information in ...preventive health care and of medical, psychological and functional treatment .... including ...methods of.... rehabilitation, education and vocational services..”.

# Insuring the rights of children

"Children's rights generate obligations and responsibilities that must be honored". (Landsdown, 2000, p.288).

# Insuring the rights of children

Our responsibility:

Document environmental constraints, limitations or barriers with ICF codes depriving the rights of the individual child

Document environmental constraints in population - toward an "epidemiology of rights"

# Documenting rights of the child: ICF-CY environmental factors

- Integrity a person: e570-social security
- Right to life/survival: e1100/1101-drugs
- Identity e550-legal
- Family environment: e310-family
- Protection from exploitation: e545-civil
- Protection in institutional care: e340-personal care
- Education e585; 586-education
- Highest allowable health e580-health

# Documenting individual and population rights with ICF codes

Constraint or limitation	Individual child with disability	Population indicator
Availability	e1100.3 medication	7.2%
Access	e1503.3 design of public school	4.7%
Accommodation	e1251.2 assistive communication	3.4%
Affordability	e5400.3 transportation	9.1%
Acceptance	e430.4 people in authority	5.7%

# Our task

" .....children are the subject of rights,  
.... those rights impose obligations on  
adults to insure their implementation"  
(Landsdown, 2000, p.286).

We are the adults....