

The Way Forward: Closing the Gaps

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What is Intellectual Disability?

- Clarke & Clarke (1958) *“mental deficiency is a social-administrative rather than a scientific concept, varying in different countries and within different countries at different times”*
- Are the current definition and classification systems appropriate?
- New ways of thinking about intelligence – are the notions of adaptive behaviour/social competence more useful?
- Is it a deficit, a disability or a disorder? – do we need a metasyndromic approach as in the area of dementia (Luis Salvador–Carulla)

Where Have We Come From?

- 1961 – USA President's Panel on Mental Retardation
- 1964 – Harvey Stevens President of IASSMD & AAMD

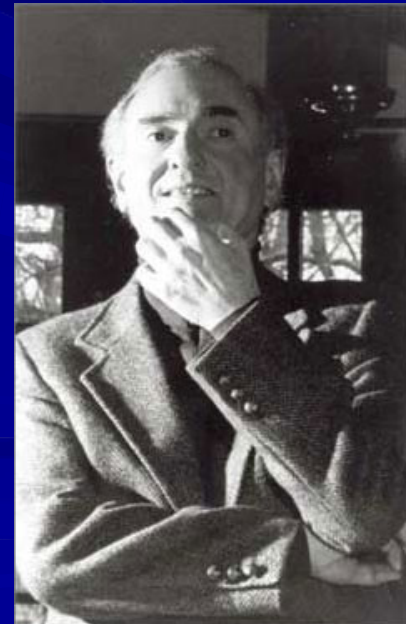
“persons with an intellectual disability were viewed not as second class citizens, but as people who possessed no citizenship”

- 1971- UN Declaration of General & Specific Rights of the Mentally Retarded
- 1975 – UN Declaration on the Rights of Disabled People

- Deinstitutionalization & Community Living
- Advocacy of the Champions
 - Nils Bank-Mikkelsen
 - Bengt Nirje
 - Wolf Wolfensberger
 - Gunnar and Rosemary Dybwad

Where have we come from?

Normalization





Where have we come from?

Deinstitutionalization



But Have We Achieved Community Inclusion?

- At school?
- At community living?
- At work?

Threats to the Realization of Human Rights

- Utilitarian individualism & meritocracy
 - loss of community
- Neo-liberal economic policies
 - Commodification of people with disabilities
- Genetic engineering and the designer baby phenomenon
- Community attitudes

What are the Gaps?

- Intellectual disability a low priority in government policy
- Gap between needs and resources
- Personalised models of support
- Lack of accountability at structural, process, outputs and outcomes levels
- Indigenous research with partnership with people with an intellectual disability and families

Limitations of the Rights Discourse

- The moral language of rights is neither sufficient nor necessary to ground moral responsibility for people with a disability,
- Without people who have sufficient moral character to care, rights can do little to sustain the mentally disabled and their families. People can be forced to comply, but they cannot be forced to care.

Hans Reinders (1999)

- Laws and legislative work cannot provide total answers to problem solving and proper action with regards to realisation of human rights. These can only come into existence in the full cultural and human context.

Bengt Nirje (1985)

Challenges

- Competition for resources by the needs of the general ageing population
- Early ageing by people with intellectual disability
- Ageing parents of people with an intellectual disability

■ Competition for trained and committed staff to support people with an intellectual disability in:

- Employment
- Community living
- Education
- Relationships
- Leisure and recreation

■ Environmental degradation

The Way Forward - 1

- Use the ICF

ICF Aims

- to provide a scientific basis for understanding health and health related states, outcomes and determinants
- relevant to all persons in the population (not limited to those with a disability)
- to establish a common language to improve communications
- to permit comparison of data across
 - countries
 - health care disciplines
 - services
 - time
- to provide a systematic coding scheme for health information systems

Conception Of Disability

- **Medical Model**
- **Minority Model**
- **Negative view**
- **Categorization**
- **Patronization**
- **Dehumanization**

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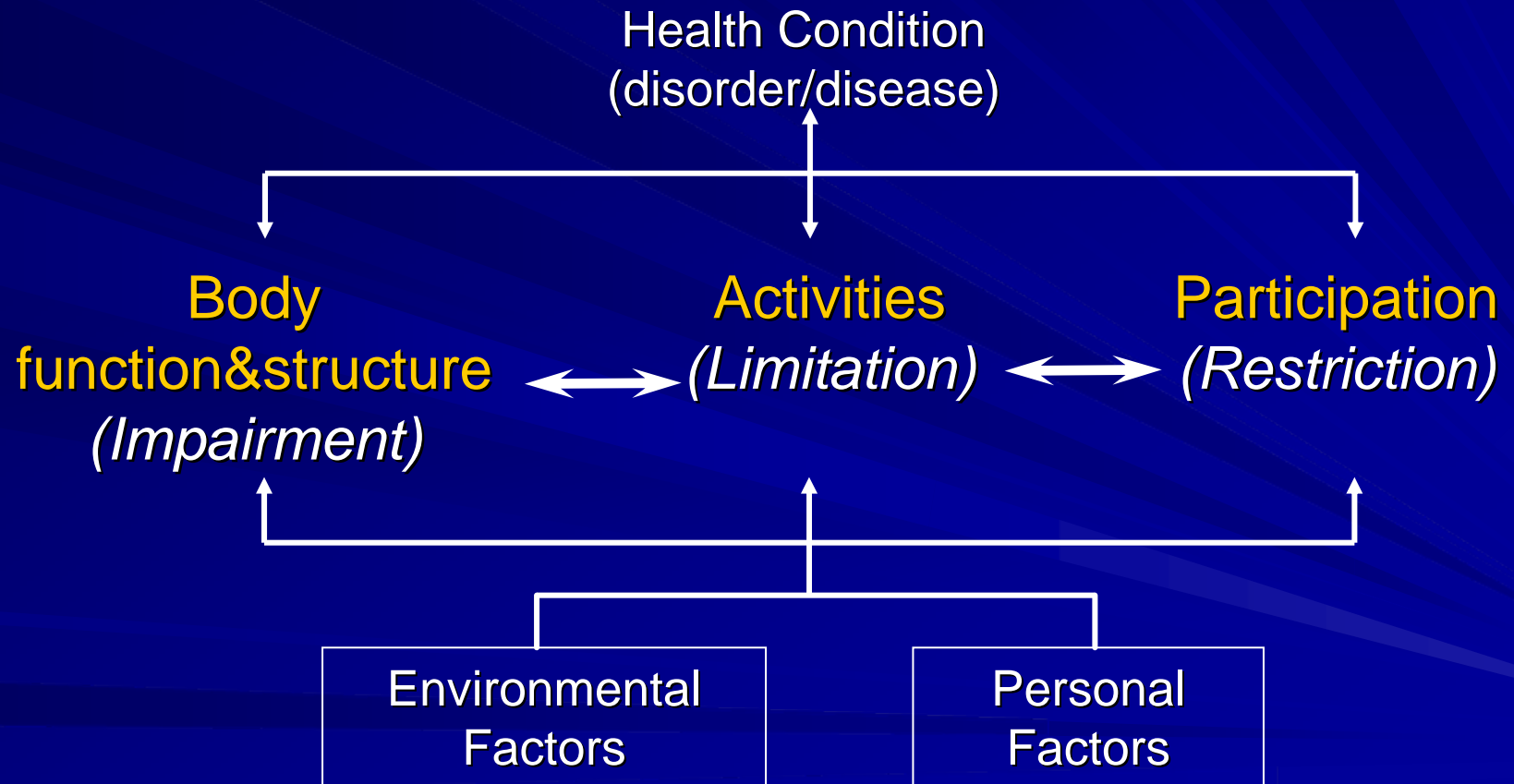
- **Social Model**
- **Universal Model**
- **Neutral Approach**
- **Multidimensional**
- **Equalization**
- **Humanization**

Universal Model

- Health is a basic human right
- No one should be discriminated against on the basis of their health status & functioning
- Most people have some “disablement”
- Disability is a fact of life
- Functioning could be altered at
body – person – society levels – solutions could be found at all these levels

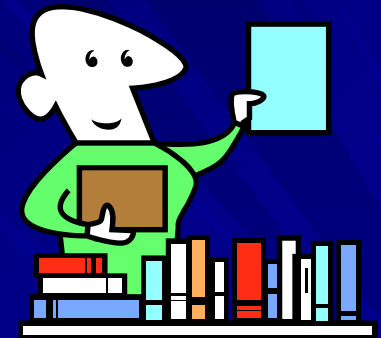


Interaction of Concepts



Applications of ICF

- Statistical
- Research
- Clinical
- Social policy
- Educational



The Way Forward - 2

- Put the person with a disability at the centre

Commentary

“The current paradigm of service delivery in the welfare area may be described as *supply-side service delivery*....in hospitals, in welfare agencies and psychiatric care units, in nursing home dining rooms and day centres for people with intellectual disabilities, this paradigm still rules: services are dispensed to disconnected and passive clients in programmatic modules, administered by departmental ‘silos’, segmented by jurisdictions, fractured by disciplinary demarcation, and delivered by agencies that are charged with accountability, not to their consumers but to their funders.”

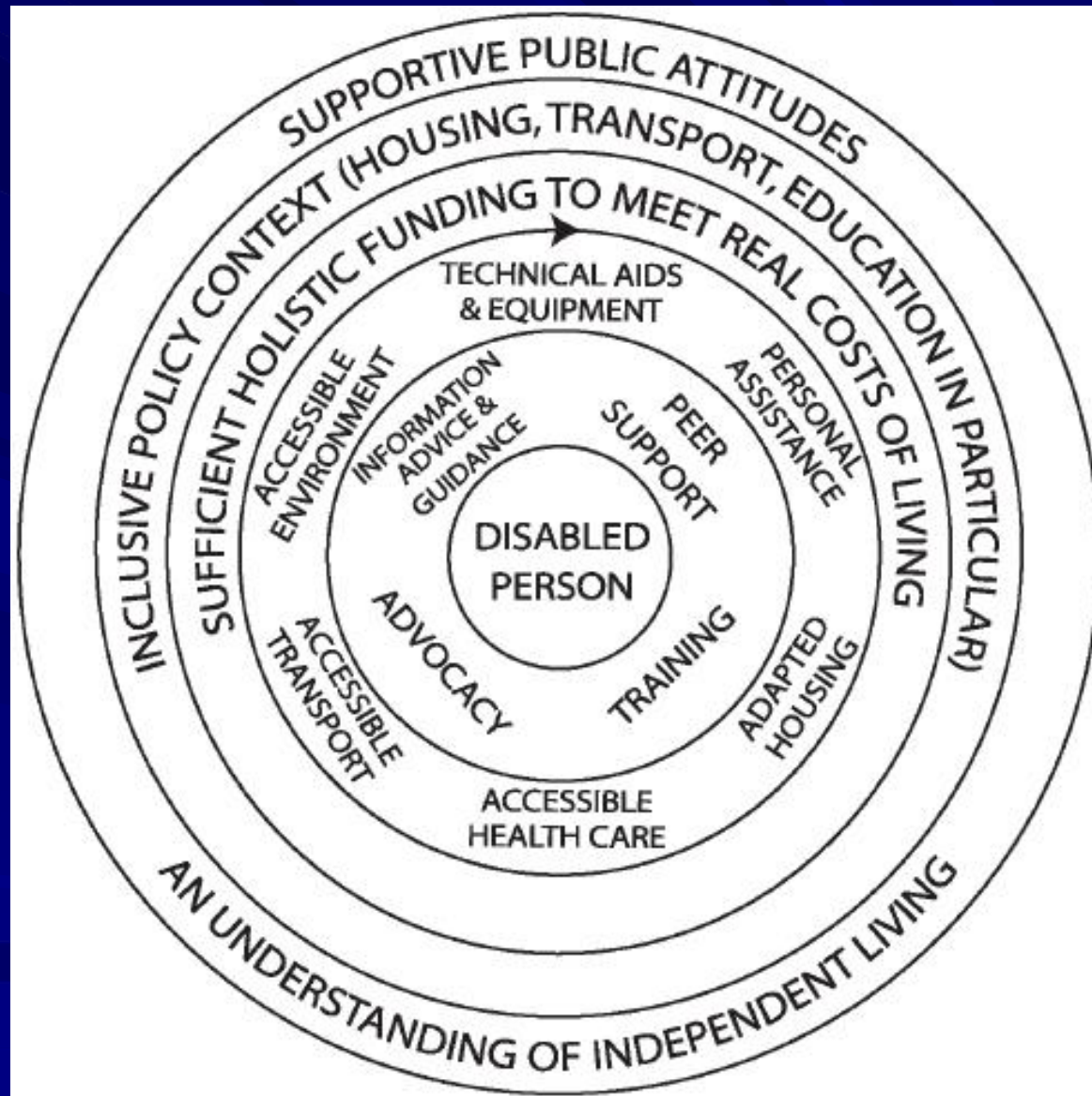
Vern Hughes, 2006

- Disability services have been supply driven
- Consumers and families have been disempowered
- No evidence of outcomes despite increases in funding
- Need for a new paradigm that recognises consumer/family involvement in policy development – put the person at the centre
- Develop social capital around the person with a disability and build community capacity to provide formal and informal supports

A New Paradigm

- Personalised support
- Consumer/family support
- Individualised funding
- Person-centred planning
- Empowerment of people with disabilities & families
- System-wide intermediaries between consumer and provider
- Long-term financial asset development

A model illustrating a system that aligns different levels of support around the person with a disability (Demos,2005)



The Way Forward - 3

- Develop collaborative research and training to build local capacity in the middle and low income countries
- Build local data bases with valid and reliable information

The Way Forward - 4

- Develop coalitions with other advocacy groups to advance political action – e.g.
 - Civil rights groups
 - Feminist movement

The Way Forward – 5

- Apply universal design together with specialised back-up services

The Way Forward - 6

■ ATLAS Mark 2

Implement monitoring and compliance mechanisms to report on:

- Structures
- Processes
- Outputs
- Outcomes



QUALITY OF LIFE

One of the major things that has gone wrong today is that governments have become so far removed from the average person that there is no connection between them....We have to get back to communities; and gain greater autonomy to determine the future of our own community.

Suzuki, 1991

CARPE DIEM !!

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