Participation as a means or an end within HTA and ICT: lessons from a disability studies approach
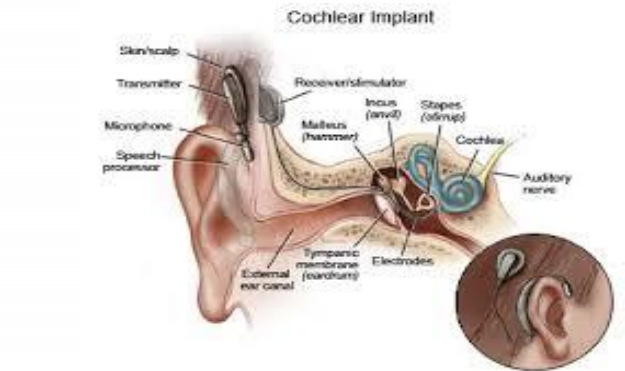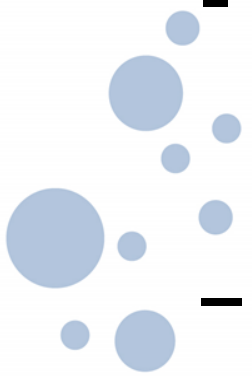
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LABERS UBO Brest

Technologies and disability have a long joint history. But HTA has until recently largely ignored this sub-population

- A 2005 Canadian report[1] on HTA focusing on enhancement[2] suggests that HTA has:
  - rather ignored disability
  - treated it through an individual biomedical model
  - and disabled people as 'patients'
  - But we do have ATA assistive technology assessment for instance…
  - Evidence: lack of Google hits on HTA & disab* on HTA sites

1. The triangle of enhancement medicine, disabled people, and the concept of health: a new challenge for HTA, health research, and health policy AHFMR 2005
2. Enhancement is argurably the positive cousin of disability

We should treat technologies symmetrically and inclusively

- Technology can have <u>both</u> Positive and Negative effects on well-being and participation.
- It can also be accepted or rejected
- *From an HTA perspective I see no fundamental reason why technologies in relation to people with disabilities should be considered separately*

Ethical Justification or Criticism

- From an ethical perspective It may receive justification or be criticized on different grounds:
    - Consequentalism,
    - Social justice,
    - Rights & Dignity

Principal Grounds of justification

- Consequentialism: One examines the outcomes or likely outcomes of using the technology; (Harms & Benefits)
  - Social justice: One examines how the technology impacts or is likely to impact on equity, such as health inequalities.
- Deontology: Rights & Dignity : Are persons being treated as ends unto themselves? Is their autonomy respected ?

Health technologies are about health…
Which health or dimension of health are we seeking to promote ?

The model of health and health inequalities, we adopt has considerable repercussions for people with disabilities.

Positive ? Negative ?   Social ? Intrinsic good ?

Instrumental good?

 Enhancement ? (Transhumanism)

The case of DALYs

- DALYS (Mont, 2007) where disability is defined as 'a loss of health' pose particular ethical challenge
    - Implicit judgment of some lives being of less value than others.
- Tension with interactive models of disability such as the ICF (International Classification of functioning, WHO, (2001) Disability and health and Disability Creation Process PPH, Fougeyrollas, et al, (1996, 2010)

Technologies have much in common with technology users. They are profoundly social.

- Technology is not in a vaccum. It is embedded in historical and social context and indeed creates new contexts.
- People and people with disabilities have different aspirations.
- They are also embedded in social contexts and environments.
- *One could say that the journey technology and people with disabilities have come on has followed similar phases.*
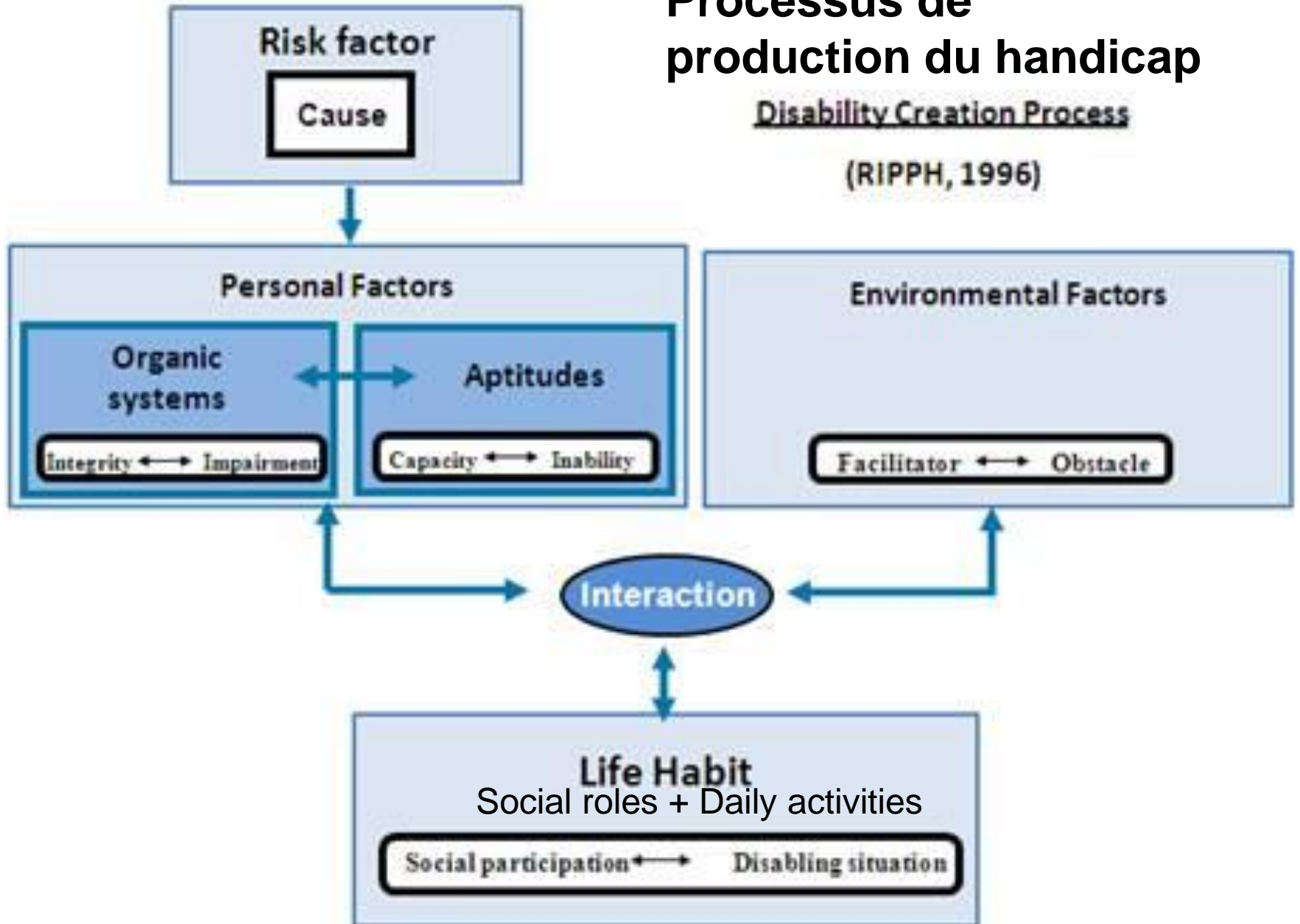
So rather than treat a person with disabilities as a biomedical problem…

- it is vital to capture these social and environmental aspects.

- This is well achieved by the « Processus de production du handicap » (PPH) The Disability Creation Process (Fougeyrollas, 1996 et al)

Processus de production du handicap

Disability Creation Process

(RIPPH, 1996)

Risk factor — Cause

Personal Factors
- Organic systems — Integrity ⟷ Impairment
- Aptitudes — Capacity ⟷ Inability

Environmental Factors — Facilitator ⟷ Obstacle

Interaction

Life Habit
Social roles + Daily activities
Social participation ⟷ Disabling situation

La Situation de handicap

In French we speak of « la situation de handicap »

Different dimensions such as protection of bodily integrity, capacities, environments, social roles and daily habits.

How social participation is either restricted or enabled

Social participation is a good indicator for assessing the value of an intervention, policy or technology

ICT but also HTA is also a kind of technology.

- And that participation can also be a means for favouring good design
- HTA and ICT should take on board not just their outcomes, but how they are designed and implemented
- And the persons concerned have the possibility to influence design and implementation.

Two quick examples

- ParticipaTIC project on creating on-line learning training for leaders of Disabled Persons Organizations
- Doing quantitative surveys inclusively

Projet ParticipaTIC 2016-2019, n°2016-1-FR01-KA204-024074
Développement des compétences des acteurs de l'inclusion
sociale des personnes handicapées

https://giffoch.org/

Partenaires :

France : Collectif Handicap 35
Roumanie : SSEO Technical Assistance srl
Belgique : GRAVIR asbl
France : Handicap International
Belgique : Haute École Libre de Bruxelles
Ilya Prigogine
Belgique : Haute École Louvain en
Hainaut
France : Institut de Formation en
Pédicurie - Podologie, Ergothérapie et
Masso- kinésithérapie-IFPEK

France : Université Catholique de
Lille (Fédération Universitaire et
Polytechnique de Lille)
France (Coordinateur du projet) :
École des Hautes Études en Santé
Publique

Suisse : ASA-Handicap mental, avec
le soutien financier de Movetia
(subvention Confédération suisse)

is an Erasmus + project and online moodle based training programme for Disabled leaders http://participatic.eu/en/home/ (see following slide for details on partnership)

3 main objectives: Competencies for leaders of Disabled persons organisations

- To defend Association members rights and plead the cause of people with disabilities

-   To sound out their members views and give them voice

-   To create an online community

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- The 3 year project incorporates people with disabilities in the iterative design, the production and testing of the training modules

- Qualitative interviews and focus groups with people with disabilities on ergonomics.

- Attention to web-page design and Moodle modules which will be adapted to different types of capacities

- Translation of language into Easy to Read & Understand

- Universal design principles by default

Conducting a quantitative survey by questionnaire on quality of life of school students

- Questionnaire produced and survey of adolescents carried out

- But no adolescents with intellectual disabilities (ID)were in the survey…

- A praiseworthy venture: Survey adapted so as to carry out new separate survey on adolescents with I.D.

But is this the end of the story …

EHESP

Well, no…

- It will be difficult to interpret the results in relation to the previous survey : Different sample, time, investigators, questions…

- So if the first questionnaire had been written in Easy to Read & Easy to Understand language all adolescents would have been included from the very start.

- The same questions being asked to everyone avoiding stigmatization & methodological issues

Take home messages

- Technologies and people are deeply social.

- Which health are we seeking to promote and evaluate ?

- This has profound implications for measuring health and health inequalities and impact on people with disabilities.

- Analyse situations rather than individuals as asocial biomedical entities

Lessons:

- Through adapting systems and their evaluation by taking into account the needs and views of disabled people we will cater for all members of society.

- Participation is a good measure of the inclusiveness of our society and its technologies.

Thank you

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