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*Marguerite Schneider:
Participation and Environment in the ICF
and measurement of disability*

Participation and Environment in the ICF and measurement of disability

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Overview

This paper will look at the following issues:

- Changes from ICIDH 1980 to ICF 2001
- Concept of Environment and environmental factors
- The information matrix
- Current surveys including a look at the similarities and differences in health and disability surveys
- Suggestions for national surveys on disability and health
- Conclusion

ICIDH (1980) to ICF (2001)

Some of the main changes from the ICIDH (1980) to the ICF (2001) include:

- Moving from a classification that describes the consequences of diseases in a linear, progressive manner to one that describes components of health associated with health conditions. The consequences of diseases cannot be assumed; the components must be described and documented for each individual.
- Explicit incorporation of environment as an independent aspect to describe
- Use of neutral terms with the ability to describe both positive and negative aspects of functioning
- Specification of the information matrix

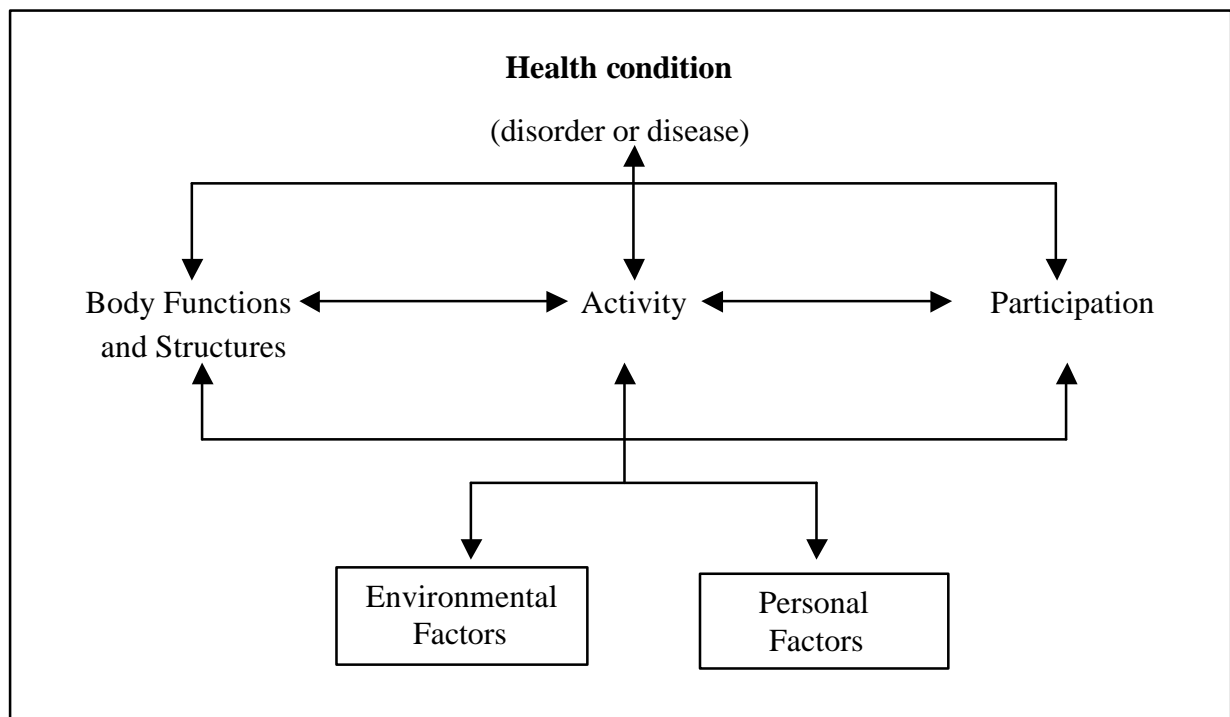
The ICF model is

- *universal*: continuum of disability; not binary categories of disabled and non-disabled
- *interactive*: complex, multilayered interactions between person, their health condition and environmental factors
- *integrative*: biopsychosocial model

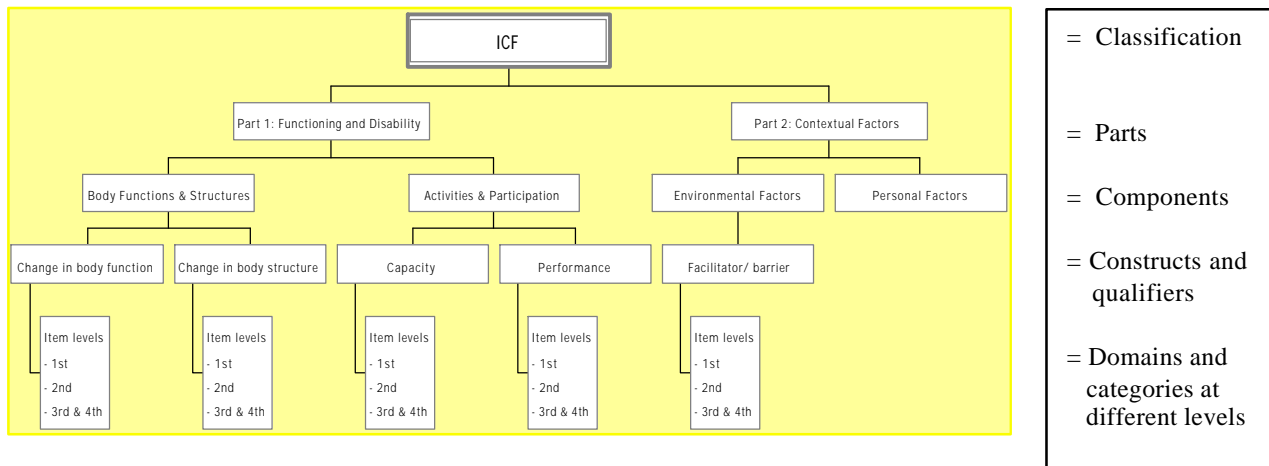
The foundations of the ICF include:

- Consideration of human functioning in all its aspects and not looking merely disability
- Advocating a universal model, which describes everyone's experience, not only those of a minority group of disabled people
- Integrating both medical and social aspects into one, integrative model – biopsychosocial model
- Highlighting the interactive nature of functioning and disability, as a complex, multi-layered phenomenon, and discarding the linear, progressive model put forward in the ICIDH 1980
- The notion of parity, with different etiologies or causes having similar outcomes of disability
- An inclusive approach which not only considers the person, but the context or environment in which the person lives
- Cultural applicability where the classification provides a list of domains relevant across all cultures
- Operationalisation of concepts
- A life span coverage.

ICF Interactional model



Structure of ICF



Environment

The ICF Part 2: Contextual factors has two components:

- personal factors (not classified in ICF)
- environmental factors (ICF EF Section)

Environmental factors (EFs) are external factors that make up the physical, social and attitudinal environment in which people live and conduct their lives. EFs form part of both the immediate and distant/ background environments. The same environmental factor can operate as a facilitator or barrier within a person's immediate environment as well as within the background environment. An example is that of attitudes as experienced by an individual as well as a background factor influencing policies.

The ICF has 5 chapters making up the environmental factors section. These include:

1. Products and technology: the natural or human-made products or systems of products, equipment and technology in an individual's immediate environment that are gathered, created, produced or manufactured.
2. Natural environment and human-made changes to the environment: animate and inanimate elements of the natural or physical environment, and components of that environment that have been modified by people, as well as characteristics of human populations within that environment.
3. Support and relationships: people or animals that provide practical physical or emotional support, nurturing, protection, assistance and relationships to other persons, in their home, place of work, school or at play or in other aspects of their daily activities.
4. Attitudes: the attitudes of those people (external to the person whose situation is described) that are the observable consequences of customs, practices, ideologies, values, norms, factual beliefs and religious beliefs.

5. Services, systems and policies: Services that are the provision of benefits, structured programmes and operations; Systems that are administrative control and monitoring mechanisms; and Policies that are the rules, regulations and standards.

Environment and functioning

Disability is the outcome of the interaction between a person's health condition and contextual factors. In order to fully describe this interaction, the following elements should be considered:

- The person and their health condition (personal factors + using ICD-10)
- The external environment described by an outsider (using the EF section in ICF)
- The person's own description of their external environment (using the EF section in ICF)
- The person's appraisal of their environment and rating of satisfaction (Not using ICF)
- Outcome (using components of functioning in ICF)

Environmental factors have a fundamental link to the components of functioning and the outcome of disability as an impairment, capacity limitation and performance problem.

- **Body function/structure and Capacity:**

Body function and structure as well as capacity are independent of environment for their definition. However, the manifestation of a latent health condition *may* occur through impact of environmental factors. Examples of this would be an underlying condition of hay fever, with symptoms that only manifest in an environment with high pollen count; and the health condition of night blindness that only manifests itself when there is a lack of light, thus causing difficulty in reading.

While the definition of body function and structure and capacity is independent of environment, the measurement of these is always within an environmental context that can be described using the environmental factors framework.

- **Performance:**

The environment is integral to the definition of performance, and, therefore, the description of environmental factors must be part of describing the performance of a person.

An example of this would be a performance problem in mobility occurring only in an inaccessible building for person with capacity difficulties in walking. The performance problem does not occur when the buildings are accessible.

Information Matrix

Domains		Qualifiers	
		<i>Performance</i>	<i>Capacity¹</i>
d1	Learning and applying knowledge		
d2	General tasks and demands		
d3	Communication		
d4	Mobility		
d5	Self-care		
d6	Domestic life		
d7	Interpersonal interactions and relationships		
d8	Major life areas		
d9	Community, social and civic life		

The information matrix provides a list of domains ('d') that can be assessed using two constructs, performance and capacity. Capacity can further be assessed with or without assistance.

- Performance is a qualifier that describes what an individual does in his or her current environment or what happens when a person with a particular health condition, impairment or capacity limitation interacts with a particular set of environmental factors.
- Capacity is a qualifier that describes an individual's ability to execute a task or action. It is the highest probable level of functioning in a given domain *at the moment of ICF profiling* (i.e. it is not the person's future potential). Capacity is always assessed within a context (e.g. a uniform or standard environment). Thus, it is referred to as an environmentally adjusted ability.

WHO sees the information matrix as presenting the necessary information for reporting on a population's functioning. The issue of how capacity and performance relate to the components of Activity and Participation remains an area for further research. The information matrix is compatible with all four options set out in ICF for conceptualising A and P.

Review of current surveys on disability

Although there is much development in the area of disability surveys, (this meeting being one indication of this), there are some observations that should be noted concerning the

¹ Capacity can be coded with and without assistance, although capacity without assistance is sufficient.

current structure of disability surveys. Firstly, these tend to focus on activity limitations and/or impairment.

Wording

Furthermore, the wording of questions varies greatly which severely hampers efforts to compare data across surveys. The different wording of questions includes:

- ‘Do you have difficulty...’
- ‘Are you able to...?’
- ‘Do you do...?’
- ‘Do you have problems with...?’
- Asked with and/or without personal or technological assistance

Are these surveys asking about capacity or performance? The lack of or limited reference to the context the respondents should consider in responding, makes it difficult to decide.

Domains covered

The surveys ask few questions on participation and environment and are limited in the domains they cover as well.

The *Activities & Participation* (or ‘D’) domains generally covered include:

- education and employment (phrased as performance question)
- some surveys include other major life areas such as friendships, family life, making decisions, etc.

The *environmental factors* (‘E’) domains generally covered include:

- use and availability of assistive products and technology
- accessibility of the environment
- availability of services (health, welfare, education, rehabilitation)
- little or nothing on policies, attitudes, natural environment, planning and design

What do disability surveys measure as disability?

1. A priori definition of disabled versus non-disabled

Some disability surveys, especially the earlier ones, use an a priori definition of who counts as being disabled. The aim of the survey is to count the number of people who fit this definition of being disabled in a total population. The data can then be analysed according to the two groups – disabled and non-disabled – for a number of different variables.

This type of survey will ask questions like ‘Are you deaf, blind or have a physical disability?’ Many census questions use (or used) this format.

2. A posteriori definition of disabled versus non-disabled

More recently, surveys have moved towards a more a posteriori definition of disability. These measure capacity and performance across a number of domains. This second type resembles more the type of surveys we see happening - e.g. HALS (Canada), HID (France), disability survey in South Africa, Spanish survey on disability, NHIS-D (USA), the Netherlands survey, to name a few.

These surveys ask questions on difficulties people have in a number of domains, where a person's profile might show they are disabled in one domain but not in another. The disabled/non-disabled categorisation is made at the domain level, not as an overall category of being disabled or not.

This approach allows for analysis at the individual domain level; for example, comparing the experience of disability in mobility vs socialising vs communication, etc., and the impact of environmental factors on these different domains.

The information is more specific and precise.

The resulting profile of a person's functioning across a number of domains is the same as that person's health and health-related state across different domains.

Advantages of the 'a posteriori' approach:

- It supports the universal approach advocated by the ICF. Everyone experiences impairments at some point, and this experience will be counted in the a posteriori approach but not in the a priori one.
- Decisions about creating categories of who is disabled and who is not can be made at point of analysis; for example, through analysis of the experience of people with disability in one, two or three domains; employment of people with disability in one domain versus those with disability in another domain; and so on.
- There is no need for a definition of who counts as disabled and who does not. What needs to be defined is what counts as a capacity limitation or performance problem in the different domains.

Disability and health surveys

Let us now look at the issue of health and disability surveys. What are the commonalities and differences between these two types of surveys?

Firstly, their similarities:

Both types of surveys are looking at the health of a population and the information collected in each type of survey should complement each other and form a comprehensive picture.

There should be a common list of domains included in both surveys as shown in the table. The list includes both health and health-related domains.

The questions are asked in terms of 'How much difficulty have you had in the last 30 days...?' in WHO DAS and WHO surveys

List of health and health-related domains

<p><u>Health domains</u></p> <ul style="list-style-type: none"> • Vision • Hearing • Speech • Digestion • Bodily excretion • Fertility • Sexual activity • Skin & disfigurement 	<ul style="list-style-type: none"> • Breathing • Pain • Affect • Sleep • Energy/vitality • Cognition • Communication • Mobility and Dexterity
<p><u>Health-related domains</u></p> <ul style="list-style-type: none"> • Self-care: Including eating • Usual activities: household activities; work or school activities • Social functioning: interpersonal relations • Participation: societal participation including discrimination/stigma 	

While both health and disability surveys collect information on an individual's and population's overall health, the focus of each differs. The health survey will focus largely on the health condition (e.g. a stroke), its determinants (e.g. smoking, high blood pressure), the prognosis (e.g. permanent damage, possible recovery, recurrence), health interventions (e.g. hospitalisation, medication) and satisfaction (e.g. with health care received, with overall condition).

The disability survey will focus on the health condition (e.g. stroke), level of functioning at body, person and societal levels (ICF domains), assistance required (e.g. walking frame, personal assistance), environmental facilitators and barriers (e.g. attitudes, services), and satisfaction (e.g. with services received; with level of health in terms of functioning).

A Common Survey Instrument

In order to be able to compare health and disability survey data between surveys and across countries, a common survey instrument or set of questions needs to be developed. Such a common survey instrument must have the following basic features and key psychometric properties:

- *cross-cultural applicability* – clear and unambiguous questions that have the same meaning when translated into different languages and trigger similar cognitive processes, and are relevant in different cultures;
- *reliability* – on application at different times within a realistic interval it must provide consistent results;

- *validity* – it must be as robust and valid as known reference tests (or in-depth expert evaluations) and have a conceptual power (i.e. construct validity) to allow prediction of other impacts, consequences or determinants (e.g. such as outcomes, service use, costs or other known variables);
- *response calibration* – within a given culture, it must have similar calibration properties, that is to say, the scales of responses to items in the survey are consistent; this can be done through using external calibration tests;
- *cross-population comparability* – the calibration properties (i.e. the scales of responses) must be similar in different populations, that is, the same response level corresponds to same level of health in that domain. This can be done through clear and unambiguous questions which translate easily into all cultures and languages.

Incorporating the information matrix and environmental factors in censuses and surveys

So, although the title of this paper started off as being on Participation and environmental factors, it moved to being about the information matrix and environmental factors.

A number of steps need to be taken to ensure not only that surveys become more comprehensive in their coverage of all ICF components and domains, but that the data collected be comparable across surveys and across countries. We have already looked at the issue of cross country comparability. Let me end off by looking at the issue of the information matrix and environmental factors.

How can we include the information matrix and environmental factors?

1. The wording and sequencing of questions must be carefully formulated to reflect the following framework:
 - ‘What difficulty do you have in...?’
 - ‘What happens in your usual/current environment?’
 - ‘What features of the environment make it easier or more difficult for you to...?’
2. Cognitive testing should be undertaken of what context people have in mind when reporting difficulties. This should be done across a wide range of countries.
3. A wider range of A&P domains and environmental factors should be covered in the surveys. These should include the following in addition to the usual areas:
 - involvement in civil society, friendships, caring for others, etc.
 - attitudes, natural environment, design of land areas, systems and policies, services such as housing, political, legal, etc.

Conclusion

This paper has presented an overview of the newer features of the ICF, their level operationalisation in current surveys and suggestions for increasing the incorporation in future surveys on health and disability. The main points to highlight are:

- the need for more explicit questions on environmental factors and a better understanding of the role of the environment in functioning and disability;

- using the format of the information matrix to develop a comprehensive and minimal set of questions on functioning and disability;
- the need to understand the complementary role that health and disability statistics play in relation to each other to provide an overall picture of a population's health.

I thank you for your attention and look forward to further debate and discussion.