

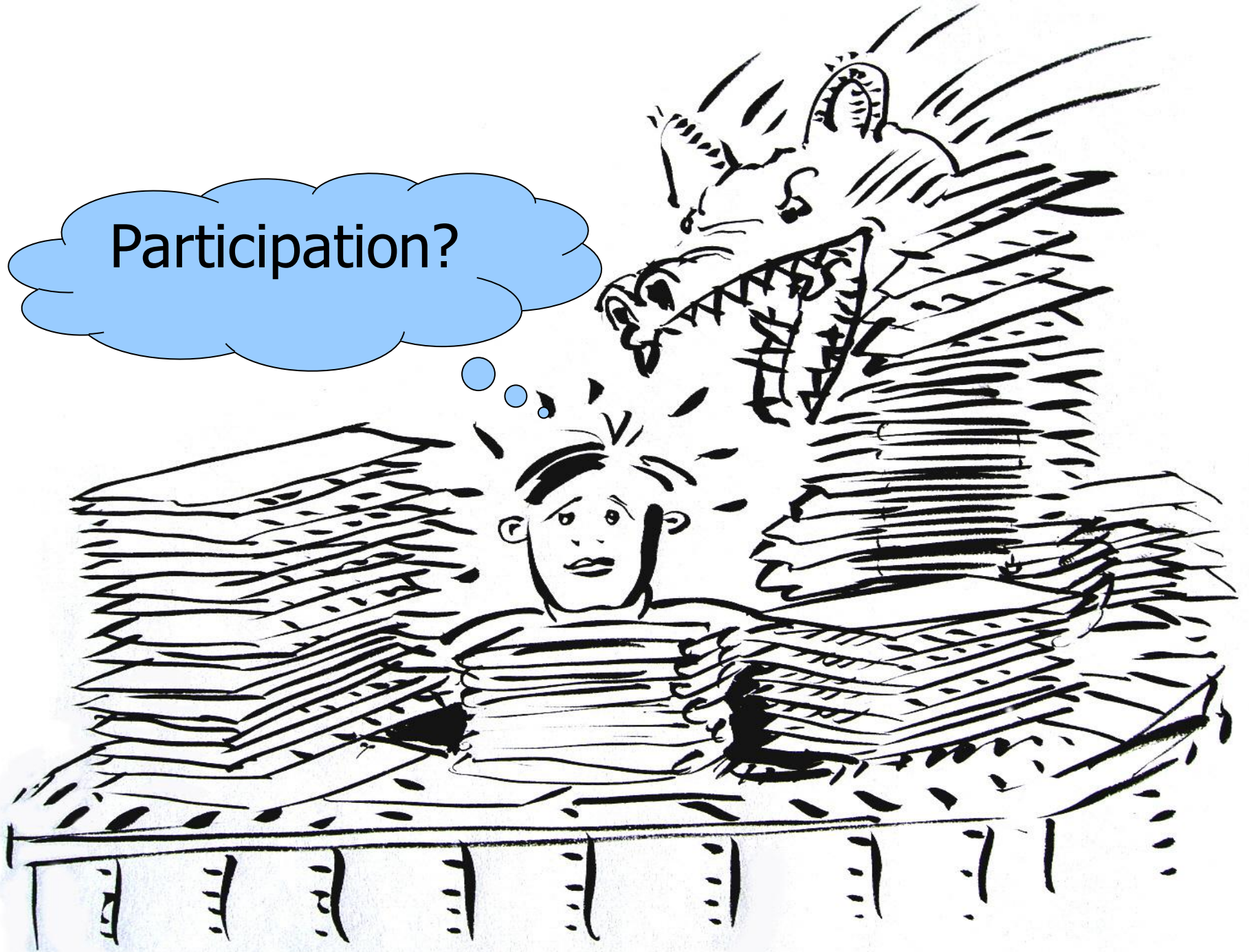
Beyond disability: exploring participation and its measurement

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Participation?



“From the time my [disease] was first diagnosed through my entry into wheelchair life, I had an increasing apprehension that I had lost much more than the full use of my legs”

RF Murphy, *The body silent*, 1990





“I have a wheelchair in my head”

“I am treated like a baby, why?”

Anonymous



Social, cultural and time dimensions are linked with opportunities for participation

	Medical view	Normalisation approach
<i>Who</i>	disability	possibilities
<i>Status</i>	patient	pupil
<i>Location</i>	institute	outside the institute special adaptations

Related to chronic illness ...

“The realisation that there was no such thing as ‘going by the book’ was an important aspect of understanding chronic illness”

“From the perspective of those with chronic illness, the biomedical model is not the ideal framework from which health care ought to be conducted”

Thorne, 1993

Social, cultural and time dimensions are linked with opportunities for participation

	medical view	normalisation approach	support model/ civil society
<i>Who</i>	disability	possibilities	rights and responsibilities
<i>Status</i>	patient	pupil	citizen
<i>Location</i>	institute	special adaptations	community

Definition of participation

- **Medical / normalisation**

ICIDH: disadvantage, normalisation

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- **Individual**

ICF: involvement in life-situations,
measured by capacity and performance

Definition of participation

- **Medical / normalisation**

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- **Individual**

ICF: involvement in life-situations,
measured by capacity and performance

- **Social**

Human being as part of society

Barriers and facilitators in society

Health as the distribution of power

Points of view



● Policy

- Health care facilities; welfare
- Have a say: civil society

● Professional

- Life style, self-management, empowerment
- Medical

● Personal experience

- Physical, mental en social wellbeing
- Care for oneself and (social) environment

The missing link



Definition of participation

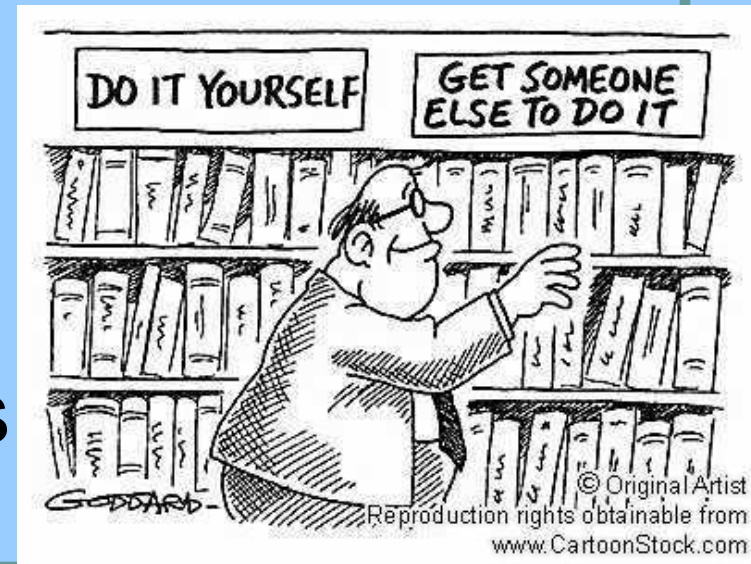
- Opportunity and choice
- Concept of autonomy

Participation is the involvement in life situations in such a way that it is meaningful for the individual.

This includes being autonomous to some extent or being able to control your own life, even if this means not actually doing things yourself.

Concept of Autonomy

- Liberal view: independence
- Ethic of care view: self-governance in social context
- Executional autonomy: ability to act
- Decisional autonomy: ability to make decisions



Participation ambitions

- “ A woman needs financial means and a room of her own, if she is to write fiction”
- “ If you have a garden and a library, you have everything you need”
- “I need social contact to feel that I exist”
- “I have one friend and that is okay, I am fine as it is”

THINK small



As professionals , do we feel enough autonomy in doing our jobs in an authentic way ?



Enablement in OT treatment

Facilitation

Guiding

Coaching

Education

Prompting

Listening

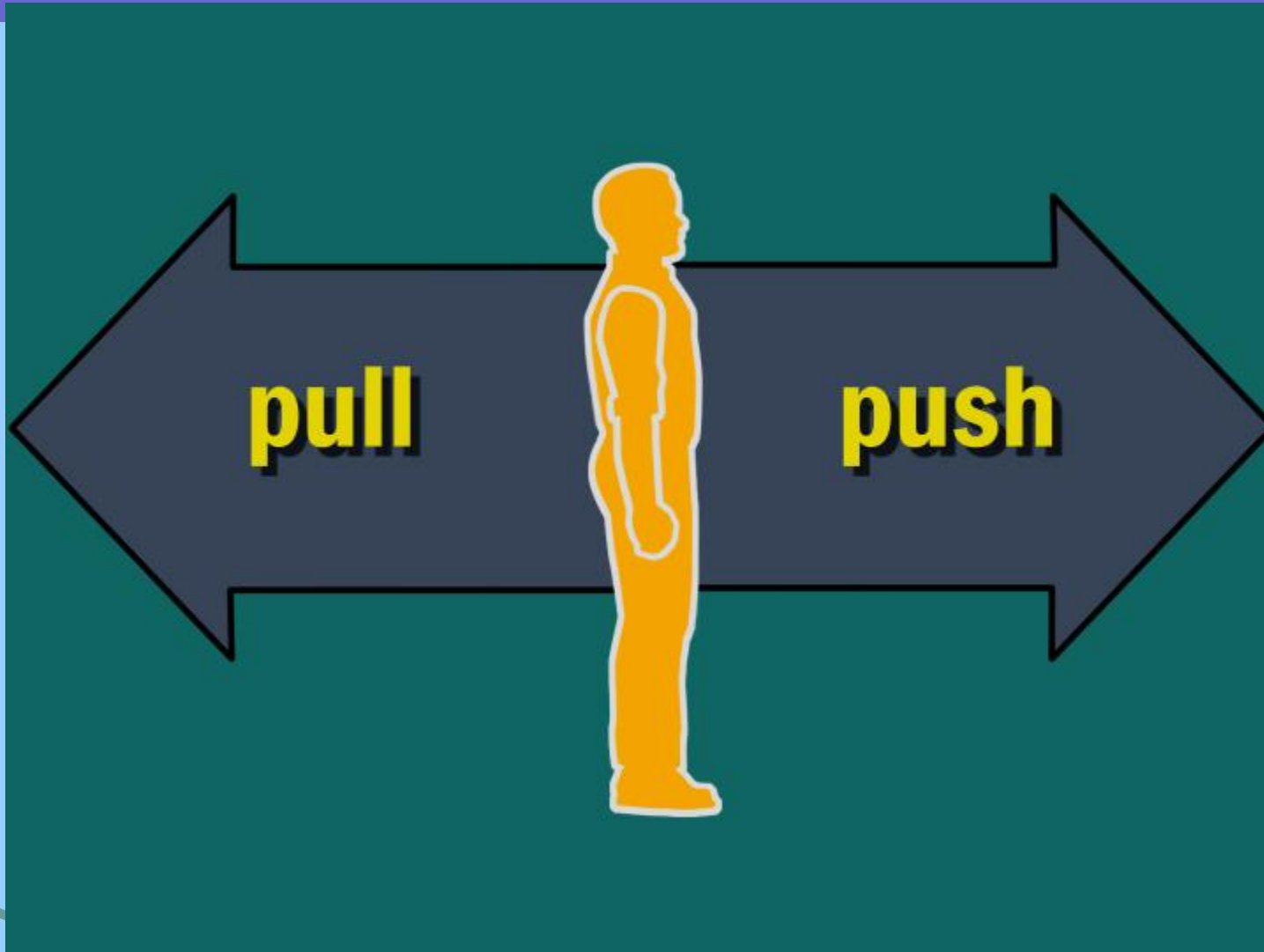
Reflection

Encouraging

Do participation and happiness go hand in hand?

	Chronic illness	Disability	Dutch work force
Work + happy	46%	18%	66%
Work + not happy	7%	6%	6%
No work + not happy	9%	34%	5%
No work + happy	39%	43%	24%

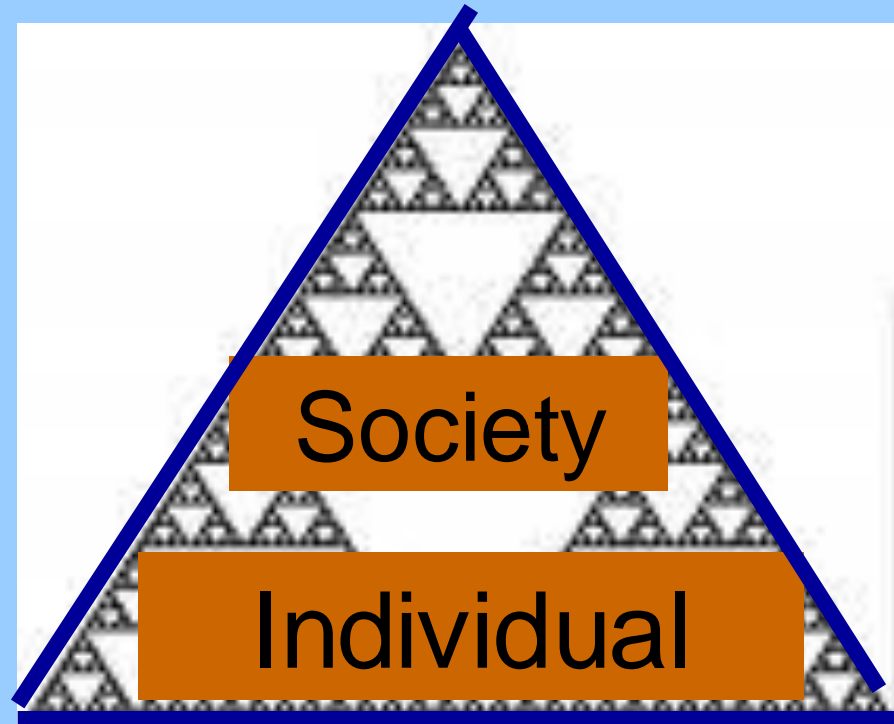
External factors of importance



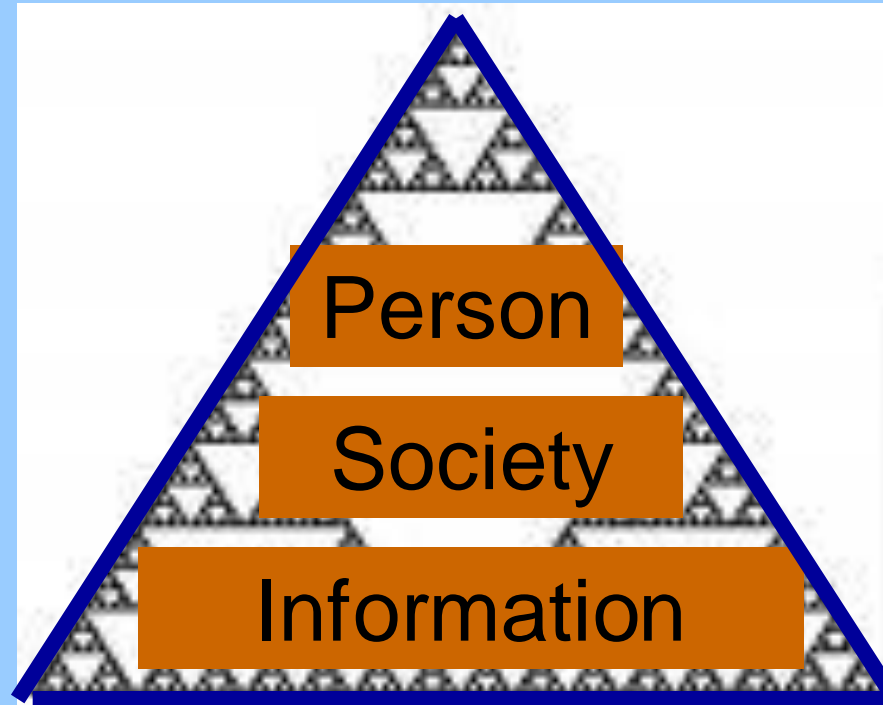
The impact of resources on social activities (results regression analysis)

	Going out evenings	Member social club	Participation as wished
No resources	-2.34	-0.89	-0.70
Social resources	0.69	0.05	0.63*
Health resources	0.51	0.43*	0.61*
Income & education	0.83	0.31	0.19

Who is responsible?



Who is responsible?



How to assess participation ?





How the patient explained it



How the OT understood it



How the questionnaire labelled it



What the patient really needed

Impact on Participation and Autonomy (IPA) questionnaire

Five domains:

- Autonomy indoors (n=7)
- Family role (n=7)
- Autonomy outdoors (n=5)
- Social life and relationships (n=7)
- Work and education (n=6)

Impact on Participation and Autonomy (IPA) questionnaire

Family role

In the context of illness or disability,
my chances of

- ..getting minor housework jobs done (e.g. cooking, making tea or coffee), either by myself or by someone else the way I want them done are
- ..fulfilling my role at home as I would like are

Impact on Participation and Autonomy (IPA) questionnaire

Social life and relationships

In the context of illness or disability,
my chances of

- ..talking to people close to me on equal terms are...
- ..having an intimate relationship are...
- The quality of my relationship with people close to me is..

Impact on Participation and Autonomy (IPA) questionnaire

Work and education

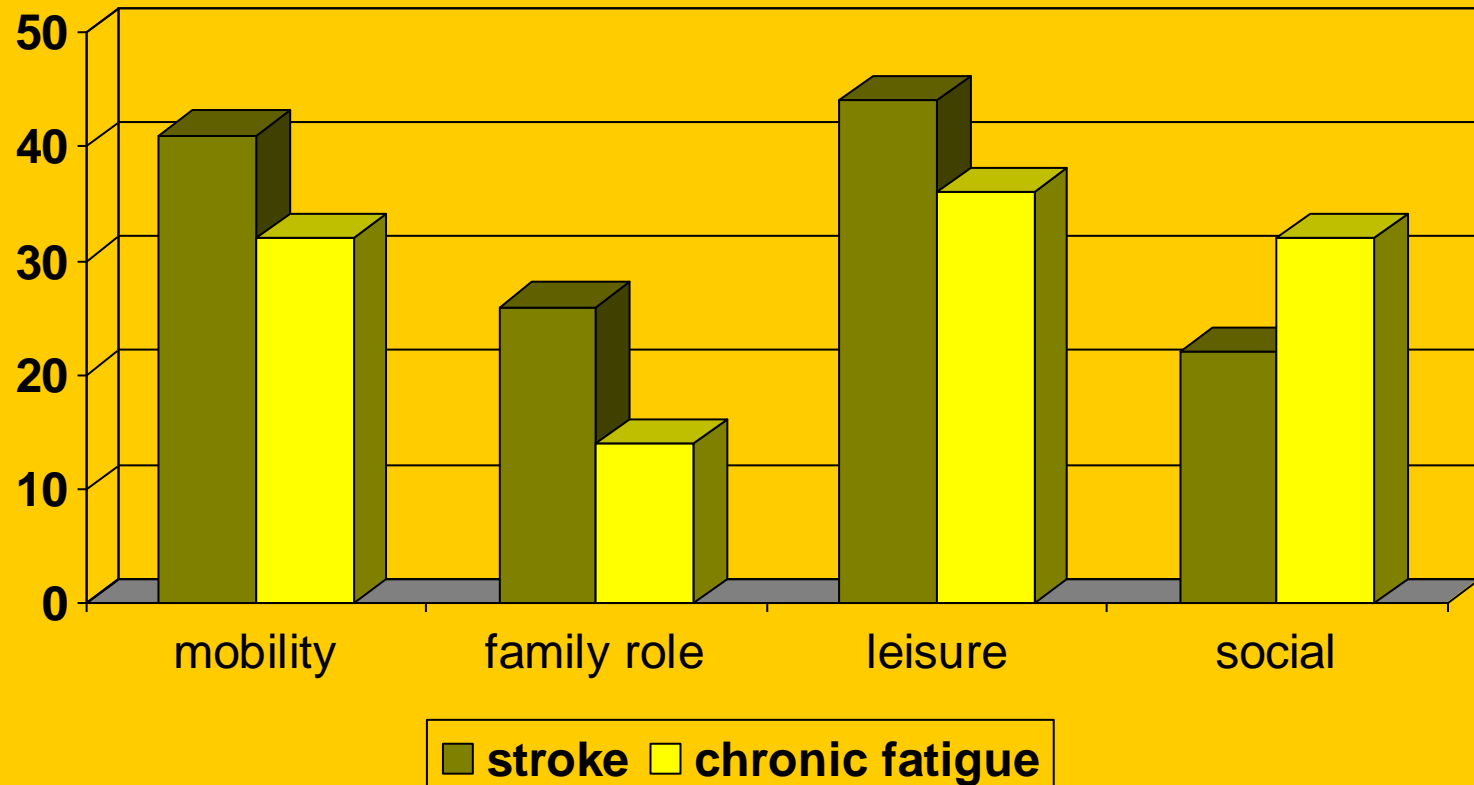
In the context of illness or disability,
my chances of

- ..doing the work or occupation I want to do are...
- ..achieving or maintaining the job I want are...
- ..getting a different job with the same or different employer are...
- My contacts with my colleagues are...

With regard to your, to what extent does your illness or disability cause problems?

1. Mobility
2. Self care
3. Activities in and around the house
4. Looking after your money
5. Leisure
6. Social life and relationships
7. Helping and supporting other people
8. Paid and voluntary work
9. Education and training

Severe problems in participation



The use of the IPA



Translations

- English version (UK / USA)
- Swedish version
- German version (Switzerland, Germany)
- French version (Canada)
- Persian
- Polish
- Italien
- Danish?

IPA - Persian version

کمکی یا همراه

ابتدا مایلیم سوالاتی در مورد تحرک شما بپرسیم. منظور امکان تحرک و جابجایی شما به هر مکان و هر وقت که می خواهید است. ما مشتاقیم بدانیم که آیا شما می توانید خودتان تصمیم بگیرید هر وقت می خواهید به مکان مورد نظرتان بروید.

- ۱. خیلی خوب
- خوب
- متوسط
- ضعیف
- خیلی ضعیف

Different contexts

- Research
- Rehabilitation practice: OT, PT, MD
 - Various chronic diseases or disability
- Home care
- Psychiatry
- Nursing

Literature IPA-development

- Handicap questionnaires: what do they assess? (1999)
- Development of the IPA (1999)
- Psychometric properties of the IPA (2001)
- On autonomy and participation in rehabilitation (2002)
- Responsiveness of the IPA (2002)
- Perceived participation of people with a chronic disabling condition (2002)

Other authors that used the IPA

- Acces to social support in SCI (Lund 2005)
- Problem experience in polio (Lund 2008)
- Physical barriers to participation in polio (Lund 2009)
- Psychometric properties of Polish IPA (Opara 2008)
- Additional topics IPA in MS (Vazirinejad 2003)
- IPA in Parkinson (Franchignoni 2007)
- Changes in participation in stroke (Mayer 2004)
- Validation of the UK version of the IPA (Kersten 2006)

Internet address for IPA

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Personal ambition...

International research

- Participation ambitions and opportunities people with a disability
- Barriers and facilitators
- Within their context

You are invited to join!

