

DISCUSSION PAPER

Subjects for visualisation and different approaches to define obstacles – and issues relevant for how to RETHINK care.

**Subjects are based on the first four UN Standard Rules for disabled people:
Awareness-raising, medical care, rehabilitation and support services.**

(Paper presented at the WHO workshop on *Rethinking Care*, Oslo, Norway, 6th June 2000)

The aim of the Rethinking Care conference is to define obstacles, ideologies and strategies for empowerment and independence for disabled people. That is a very ambitious project– on almost every possible arena in peoples life, people with impairments at the worst experience to be totally excluded – otherwise segregated or discriminated. Barriers that keep us from participation and independence can be prejudices and attitudes that do not expect us to participate, or to act in a certain way – but often an paternalistic expectation of us to resign ourselves to a patient or a sick role.

Physical barriers and solutions in the environment that exclude us from equality and participation are an insult to our dignity . Disabled people all over the world are fighting against attitudes, ideologies, religions or values, traditions and lack of knowledge that legitimatise the discrimination and segregation.

So we need to rethink.

This huge project will bee a little bit limited by the World Health Organisation's fields of activity. Even we can not isolate some arenas in life from others, there is a fact that WHO in the main are dealing with health and social services.

The Rethinking Care conference will treat social and health services related to the first four UN Standard Rules which are oriented towards people with impairment with object to create possibilities for independence, participation and empowerment in different settings as in the family, in the community and in the institutions.

These first four UN Standard Rules are

- Awareness-raising
- Medical care
- Rehabilitation
- And Support Services

I will try to suggest some approaches and subjects for further discussions and investigations to define obstacles, ideologies and strategies for empowerment, equal participation for people with impairments. But .- First of all I think it is important to clear away some difficulties regarding the concept disability.

Disability is a concept in dispute. What does the concept means? – And what does it refers to? Why this is very important to iron out is that the realisation of a situation will be dependent on the definition of the situation, which also will influence on what people see as the problem and the corresponding answer.

The interpretation of the situation will be decisive for understanding what the problems are, and what to focus on concerning solutions. There are models that describe different understandings of disability.

The medical understanding is centred on the individual. According to this understanding “disability” summarise different individual, functional limitations caused by physical, mental intellectual, or sensory impairments. Disabilities are according to this model understood as a description of the individual and his or her limitations. And the underpinning idea is that disabled people first of all are victims of a medical tragedy – and that the consequences of this personal , medical tragedy are not to be able to participate in the society. – So that is why we are DIS-ABLED /NOT-ABLED.

A different understanding of disability is to focus on the environment and interpret disability as a consequence of limitations in the environment and attitudes that relieve us the same values and possibilities as every body else.. This is the so called social model of disability. The model acknowledges the impairment and its serious individual consequences, but will not accept this as the reason for disability, understood as exclusion. Disability is brought upon people with impairments, but not caused by the impairment. Still there are some individual consequences from the impairment, for example; I can not walk or stand up, because my legs are paralysed, but still I am able to come to another floor, if there are a lift or a ramp at the place – and not only stairs that will disable me from come to another floor. To understand disability, as a characteristic of the individual – or as obstacles for participation will give fundamentally different addresses for the blame and therefor also different potential for improvements.

When we are going to deal with health and social , in reality, both focuses (the individual impairment and the disabling barriers) are of importance to obtain empowerment and independence for disabled people. Proper treatment of the impairment – and to eliminate disability by removing the disabling barriers and attitudes from the environment are essential to obtain equality and participation.

Medical care is a service that focus on the individual and his or her mental or physical limitations – and are of course necessary to survive and to live - Support services are also mainly focused on the individual, but the degree of the disabling environment will also have to be central since assistants, and services and devices to live a life on many arenas to participate will have to be an issue, as well. Rehabilitation is also oriented towards – both the impairment and the environment – or I think should be – to participate in the society also the environment should be “rehabilitated” – not only the person involved.

Awareness raising is very important. How is disability understood – to where and to whom is the problem addressed?

This rule – how I understand the rule – is oriented towards – both the impairment and the disabling environment and this is where we really should rethink to improve the health and social services

I will come back to these four UN Standard rules – but first of all: What I think is important is to distinguish the individual consequences of the impairment – and the consequences of the environment design or shaping.

The problem is when both understandings focus on and emphasise different aspects and still use the term **disability**. The two different contents of the concept will lead to two very different approaches to the problems and focuses concerning solutions.

The social model is developed by disabled people themselves and focuses on attitudes and barriers in the environment as obstacles for participation. Although the impairment can be severe and give disturbance concerning health and limited and restricted movement of the body or the mental condition, they do not find their impairment as the essential obstacle or as the most important variable for participation, but realise that if the society includes and value even them the impairment will be of fewer problems.

For this group the focus will be to de-medicalise their situation – and rather stress their problems as constructed in the environment or created in the social structures and not caused by a medical problem. For them the impairment will be considered as something very different from disability and of less or no concern for their involvement in the disability movement and participation in this Rethinking Care project. They will also be much more concerned about to rethink in general – than about care. We want control and rights – not care.

Others have internalised a medical understanding or have a chronic disease or impairment that because of pain, the constantly need of medical care or other unpleasant factors keeps the attention on the impairment – and they feel the impairment as the most difficult part and as what really prevent them from participation. For this group the essential focus and issue will be their / or their relatives experiences as a patient, their medical problems, their medical needs and patients right's movement will be of importance. Even though the subject is the impairment – speakers call it disability, and they refer to these people as *people with disabilities*.

The Rethinking Care Conferences next year aim is to define obstacles and strategies for empowerment, independence and participation for all disabled people.

To do so we will invite people with impairments to define and reveal the obstacles from their point of view to visualise different aspects and obstacles. Some of the participants will be most concerned about the consequences of their impairment – and others will be most concerned about the disabling barriers.

From the original idea of having a conference mainly concerned about people with impairments in need of medical care and Rehabilitation – and because of their severe impairments, their health, geographical connection, or financial situation are mostly concerned about this medical side we have now extended the content to imply also people concerned about disability and social constructed barriers when we shall identify obstacles for participation.

It is important that all the participants both here – and at the conference - are aware of the distinction between the patient aspect and the discrimination aspect – even of course patients with impairments- also often are rejected, excluded and discriminated.

The conference will have to be aware of different models, and their consequences; especially concerning awareness raising and the underlying ideology for the other rules, their ability to define the problems in line with disabled peoples own experiences and realisations, and the models different potential for improvements.

So now, when I shall present some relevant fields, I think it is relevant to reveal – I think it is necessary to have this distinction in mind.

At the conference next year we will invite people from all over the world, with very different experiences regarding health and social services – so to find relevant fields as sources for obstacles – that all the participants will agree on, will not be easy – But actually – I do think people with impairments all over the world live on the same line of exclusion – but there are just matters or small differences of degrees of rejection, abandons and discrimination.

To rethink we need to know what to rethink –
I have tried to analyse and identify aspect in the first four UN Standard Rules to search for any possible obstacle for empowerment, independence and stronger participation for people with impairments.

Rule number 1.
AWARENESS-RAISING
First of all: What says the rule?

The rule says –

*States should initiate and support information on and spreading of knowledge about disabled people: **then I guess we talk about both impairments and disability**, -- medical implications, but also the opportunities, rights, needs, and the potential of people with impairments. States should initiate and support information campaigns concerning people with impairments and disability policies, conveying the message that people with impairments are citizens with the same rights and obligations as others, thus justifying measures to remove all obstacles to full participation. Increased self-reliance and empowerment will assist disabled people to take advantage of the opportunities available to them.*

The aim of the rule is to pay attention to knowledge and information -and underpinning ideas that will justify measures to remove all obstacles to full participation.

Knowledge and information are the two main components in the rule.

Knowledge about the impairment, about medicine about mode of treatment

To produce knowledge, to handle knowledge and to administer knowledge.

Knowledge about people with impairments – facts and living condition

Information about the impairment, about medicines - To the medical field, to patients, to people with impairments, to relatives - and to give information in public education programme.

And also information among people with impairments themselves like peer counselling

The same goes for disability.

Knowledge – to produce knowledge about disability–

But this is also a question about accepting that disabled people best can describe and know best what really prevail them from participation.

Knowledge and information about disabling factors – to the society, to the medical field, relatives, among disabled people and to the society in general.

Keywords under awareness-raising I think can represent obstacles for participation are

Attitudes/ Values Affecting the leading knowledge about impairments and disability

Communication /Collaboration Between all involved and among disabled people themselves

Competence of the information deliver, Regarding knowledge and information about impairments and disability it is important to disclose who are the premises-deliver and the distributor? On whose term are the situation defined?

Accessibility to the information –

The degree of User-control

Responsibility Who got the responsibility

And also **Financing**

I can not go in to every issue there is regarding awareness-raising that possible could be an obstacle for us to live independently and to participate in the society - –but awareness-raising is very important in connection with all the other rules, since the understanding of disability, the awareness of the problem, and how people understand and see disabled people will be crucial and decisive for the shape and the content of services related to the other UN Standard Rules. So Negative attitudes and beliefs lead to many kinds of exclusion and strange services - like. A lot of places in the world People with impairment are not given medical care at all, and if they are, - the care should maybe not even be called “care” because to been taken care of is not to be isolated and neglected people - or give paternalistic and bad services - all this is affected by the awareness about disability and superior values in the society.

So to rethink we need to also rethink the underpinning ideas – that justify today’s practice.

Rule number 2

MEDICAL CARE

What says the rule?

*States should ensure the provision of effective medical care to persons with impairments.
States should ensure that medical, paramedical and related personnel are adequately trained.
This training should be an ongoing process. People with impairments should be provided with the same level of medical care within the same system as other members of the society, and provided with any regular treatment and medicines they may need.*

The obstacles for participation and independence we will find in the content of the service today

Characteristics of service delivery

What is the service like?

Where is the service delivered?

Local – central – (transport problems.)

PHC – Primary Health Care

How does the defined purpose correspond with today's practice?

Who perform and organise the services?

Public services? – Private marked?

Professionals – witch doctors?

Nobody?

Attitudes and values will affect the services

Are people with impairments given less priority than other members of the society when it comes to general health treatment?

Why?

*Are people with impairments less worth – compared to other members in the society?
(Disabled people in most countries don't have rights.)*

Cost implications concerning treatment for people with impairments.

Is Economic consideration paramount to all others – like human worth.?

What carries most weight for decision-makers?

Economics regarding the treatment? Human worth? Capacity of work?

Tribal / or religious understanding of impairments could be that impairments are thought of as a punishment for sins. They are thought of as bad omens – and are there for rejected.

Bad

Communication/ collaboration could also be a source for obstacles

Communication and collaboration between different countries

Communication and collaboration between the professional involved

How is the communication and dialog between professionals and the user of the services?

Between the medical field and DPOs?

Competence

Of Professionals?

What about Education?

Are personnel adequately trained and equipped to give medical care?

What about methods and technology?

It is also important To give people with impairments competence themselves

Accessibility

To the services

Accessible For everybody?

Not enough/ or not the right medicine?

Services and medicine – not accessible – not enough?

People with complex dependency needs how are their needs been taken care of ?

How can developing-aid regarding medical care be subject to accessibility for disabled people? The medical language could also be an obstacle under accessibility

The degree of User control / Or participation

User participation/ influence at the individual level – versus neglect and misuse of power. Besides that people with impairment usually have a lot of knowledge about their impairments.

Responsibility

Who are responsible

Financing

And of course financing problems...

Rule number 3

REHABILITATION

What says the rule?

Retraining/ Rehabilitation, improvement or compensation for physical damage, impairments and chronic diseases. The rule demands for national Rehabilitation programmes for all diagnoses. Important are user participation and influence of the services for people with impairments. Accessibility to the local environment. Importance is attached to full participation and equality. In that case an obstacle to full participation is that other social factors, like housing, the environment, education, work etc...maybe not are enough integrated in the Rehabilitation service.

Again I will suggest some fields that may represent obstacles which may be interesting subjects for visualisation and discussions – and that can be a matter for recommendations and strategies for improvements

First of all

Characteristics of service delivery.

-How does the defined purpose correspond with today's practice?

What is the content of the services?

What does Rehabilitation mean in different countries?

-Back to the community? Also improvements in the community? What about the environment? The family? Friends? The housing situation? Work?

Who perform the services?

Public services? – Private marked?
Professionals – witch doctors?
Family – Women – Nobody?
A question of organisation?

Where

Localisation

-Community based Rehabilitation – (CBR) –

Home

Institutions?

The community – importance of the family – Women especially.

When is the services delivered?

Attitudes and values will also here affect the services

How much are the states willing to spend to achieve independence?

1) Medical recourses

2) Training assistance

3) Assistive devices?

4) Improvements in the community

5) Work on the attitude in the family?

6) In the community in general?

Other relevant issues under attitudes are:

Traditionally people with impairments are seen as unproductive and useless. Not worth spending recourses and money on.

An another relevant issue regarding attitudes will be

Attitudes among medical personnel who are submitted to a medical model of disability and a medical understanding of “normality”. Per definition, disabled people will be “the unsuccessfully”. The doctors have already failed in normalising our body functions, and we will not have high priority.

The rule says: “Within the same standard and system as other members of the society” - = How is that corresponding to today’s reality?

I Don’t think disabled people anywhere get the same references concerning independent living and as other people?

Are they compared to the population in general – or are they given a different standard - as people under worse conditions?

The medical iron grip!

The Rehabilitation is a process of internalisation of the patient-role. From now on the medical field will be involved in almost every aspect of the persons life. To see oneself as a medical tragedy or first of all a patient will start here at the Rehabilitation - helped by the medical field – and will be a career for the rest of his/hers life. (For some) To see oneself as a patient and to understand exclusion and segregation, and not to be able to participate as a

consequence of their own impairment will of course affect and influence on the persons self-respect – and how the person will look upon herself.

The sick-role

The person will be expected to act in a certain way: like grateful, humble, modest and with inferiority.

How to empower disabled people / and his/hers family through a Rehabilitation-process?

Is it possible?

Experiences from the participants at the conference

Attitudes to disabled people will also affect the

Period

For how long will Rehabilitation last?

A system to stay in as a patient for lifetime? – Or are the intentions that Rehabilitation should be a process for individual and environmental improvements?

Some diagnosis will need check-ups, follow-up and training regularly.

Communication – collaboration are other important fields

Between the medical field

Professionals – and people with impairments

But also among countries

Competence

Knowledge (education) information

Professionals?

Education?

Are personnel adequately trained and equipped for the Rehabilitation?

Information and knowledge to people with impairments

And To relatives

Accessibility

Only men? Only young? Only rich?

For people with multiple impairments? – People with complex dependency needs do they get the Rehabilitation they need?

User control

User-control in the process is very important For the individual – and DPOs. Are Disable people's organisations involved in the design and organisation of Rehabilitation services?

The person involved - and dignity is important! To make choices on his/hers own premises.

Nobody else but the person herself will be able to rehabilitate that person. She will need assistance – but she has to be in charge - this is a presupposition to succeed.

Peer- counselling – an important tool for the Rehabilitation.

**How important is the support and services given by disabled themselves as role models to give faith, competence and knowledge to other disabled people?
In daily life and in the Rehabilitation programme.**

Having an impairment oneself, is that an important capacity as an external recourse to the Rehabilitation-programme?

Balance between to assist or to control. The field will often be too protective of especially children with impairments. The children will be expected to keep up a sick-role rest for the rest of their life- and not be able to become grown-ups and independent. The cues are: to be assisted – or to be taken care of...

Responsibility

Where is the responsibility for the Rehabilitation programme?

Co-ordination problems?

Financing

Develop-aid

How is disabled peoples need taken care of when the care is organised by external recourses?

In what extend are donor countries conscious about these questions

How can develop-aid regarding Rehabilitation be subject to accessibility for disabled people?

Rule number 4. SUPPORT SERVICES What says the rule?

States should ensure the development and supply of support services, including assistive devices, personal assistance and interpreter services for people with impairments, to assist them to increase their level of independence in their daily living and to exercise their rights. States should recognise that all persons with impairments who need assistive devices should have access to them as appropriate, including financial accessibility.

Again – I got the same key-words that I think will need a investigation to reveal obstacles for participation for disabled people.

First we start out with today's practice

Characteristics of service delivery.

-How does the defined purpose correspond with today's practice – and how is it organised?

-Who perform/ are in charge of the services?

Who gives the assistance?

Family?

Women in the family?

Paid assistance?

Charity?

Community worker?

-Where is it organised?

Attitudes and values

- 1) Prejudices
- 2) Words are important: Assistance versus nursing
- 3) Support services as investments.

In what extent do the States see support services as a investment for human rights? What are *taken into a consideration?*

Old prejudices and attitudes? or maybe Economics?

Communication – collaboration

Between all the involved

- Competence

Knowledge – Information

Up-to-date information

Accessibility

To the services

User-control

The rule says: Personal assistance programmes should be designed in such a way that the disabled person using the programmes has a decisive influence on the way in which the programmes are delivered.

In what extent are disabled people free to choose when, where and who about assistance?

Considering individual wishes, concerning design, durability and age-appropriateness of assistive devices and equipment (a problem of luxury?)

Responsibility

Why don't the community provide support services according a human right perspective?

In what extent do states support the development, production, distribution or servicing of assistive devices and equipment.

The rule says: that support services are important measures to achieve the equalisation of opportunities –

Why don't the States give this priority?

In what extend are donor countries conscious about these questions

How can develop-aid regarding Rehabilitation be subject to accessibility for disabled people?

Financing

How to solve the problems with the financial disposition and accessibility to assistive devices to disabled persons in developing countries?

Assistive devices and equipment are not provided free of charge or at such a , low price that people with impairments or their families can afford to buy them.

So to summarise

Attitudes, values under here is of course also understandings and different models to understand disability

Communication/Collaboration

Knowledge/Competence

Accessibility

User control

Responsibility

Financing

will in my opinion have to be the fields that represent the obstacles for full participation regarding the first four UN Standard Rules -

To find solutions and strategies for improvements,- I think we have to make improvements on the same arenas – together with a tool like legislation.

Strategies

How to stimulate the development and production of simple and inexpensive devices?

(Local material, local production facilities and disabled people themselves involved in the production)

To achieve full social integration: care or personal assistance and organised by who?

How are the different experiences on organising assistance. Do we need a de-professionalising

How to see that disabled people themselves is able to contribute to and influence development and political priorities regarding these subjects?

What means may be employed, and what should be done in order for society and local community to take into account, to include disabled people and to have them more concerned with equalisation of opportunities for disabled people?