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## FROM PATHOLOGY TO POLITICS

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- The topic of today’s plenary session is “Ideals and understanding”, and that is why I would like you to think through the UN statement “Equality and full participation”. How do we understand the ideal of this goal? What is the meaning of the statement, and how does it affect the field of rehabilitation? We are asked to rethink, and to do so we must be able to turn some of the so called common facts up side down, and open ourselves to new, and maybe demanding, perspectives. I hope we all are willing to do so.

My perspective is naturally coloured by the fact that I am a wheelchair-user living in Norway. But still, I know that my experiences will be quite similar, in consequence, to what others with different impairments could have told you from their daily life. Certainly the examples I will refer to are different to examples from other parts of the world, - but again, from my 20 years of travelling all over the world, I know that the attitudes, and mechanisms, that lead to disabling societies are the same. Disabled all over the world are facing the same myths and superstitions. Myths based on the presumption that our lives are poorer lives, and the reason is considered to be our own biology. This myths is probably the reason why disablement has become primarily a matter of health and social welfare. It is now time to realize that disablement is a matter of human rights, and if we don’t realize this, - the chances of reaching equality and full participation will be just a dream.

We need to rethink the way we traditionally has understood disablement and therefore disabled persons. To be able to rethink, you need to use your own imagination. Therefore I will provide four pictures that hopefully can lead to new reflections and understanding.

## ❑ THE DIFFERENCE

I have called the first picture “the difference”. The motif is about equality in the context of everyday life. What does equality mean? It is a good concept, but it is not used so much in everyday life. Rather it is a concept that easily is put forward from podiums, at parties and in speeches at official ceremonies. Like a solid rock, the concept is routinely included in propositions and treaties.

Equality is not about people being the same, or becoming the same. On the contrary, it is about people being different, but still equal. It is one of those many concepts that are so fundamentally important, that is so easy to pronounce, - but still so difficult to turn into practice.

Equality has to do with what we think and say about others, - and, in particular, how we turn our words into practical consequences for their lives, and for their right to participate on an equal level - to be free citizens in a free world.

Let me add some more details, in order to fill in the picture.

Many differences between people are easy to see. For example: seeing me, it is obvious to all that I use a wheelchair. Likewise it is easy to pick out those who have a different skin colour, or are of a different gender. It is also rather easy to find out whether somebody cannot hear, is blind, or has Down’s syndrome, for that matter. But there are also a number of differences that are difficult to notice. And what we do see, is often what we choose to look for, or what we have been trained to see, - or to ignore.

The differences that I refer to when considering equality are not about biological, pathological or other bodily differences. These differences only confirm that people in fact are different. These differences make every individual unique. Without these differences we would have become homogeneous, uniform, boring and grey. Without these differences, we would actually have become less human.

Neither are the differences I am talking about very invisible, but they make many of us invisible. How is that?

In our society people create attitudes, barriers and obstacles that exclude others from taking part in the community. The very way in which we plan and structure our society has dramatic consequences for those who live there. The possibilities for self-development, independence, influence, and for taking part in society – in short – the possibility to live your life as a whole human being, is not decided by your biological status, but by unnecessary barriers that others place in your way.

So what really matter are not the pathology of the individual, but the politics of the community!

- ❑ It is about planning a society that takes into account the simple fact that people are different. Today this is not done. We develop and construct our environment as if we were all similar. This has a negative effect on some of us. Some of us get shut out. This makes us invisible. We are not equal.

Most schools are not adapted for us. We cannot shop where we want. We are shut out from using public means of transport. Information and cultural events are communicated in a way that suits the majority - not in a way that meets the needs of the listeners, the readers or the viewers.

The list is long, and it includes all aspects of social life. It is not about coincidences, on the contrary, it tells us about a systematic exclusion and segregation.

And the number of people concerned is not small: More than 500 million people are somehow affected, every day, and throughout the whole world. It is not as if we are few in numbers, it only seems that way, since we are being made invisible by exclusion.

Such politics of exclusion of course affect other people's relationship with us, either because they do not see us, or if they do, they see us sitting in specially designated places for "people like you", in the queue for the toilet for "people like you", utilizing transportation arrangements for "people like you", using separate entrances for "people like you".

This difference not only affects attitudes toward and relationships with us, - it also affects our relationship to our own selves. We are not where you are, together with you. To the extent that we are being let inside, we are often let in through the back door, to go to our designated seat. Of course this does something to us. It affects our sense of self-esteem. It creates differences. Unnecessarily. It does not make us equal.

In our world, in our time, this is acceptable. In our culture this is the rule, not the exception.

These claims are, unfortunately, neither pessimistic nor incorrect; they are in fact based on observations and experience. They are facts that can no longer be brushed aside by saying "surely, in this day and age we do more for the disabled than at any other time in history".

In 1981 the UN agreed upon the goal of "Equality and full participation". Twenty- three years have passed. One generation. Still this goal is but a dream. Still we have dreams of "a society for all". Not for a society with segregated arrangements, segre-

gated solutions and special treatment of those of us with a different pathology from the majority. Not for a society where, paradoxically, the exclusion is often financed through the community's treasury, through public budgets, and by means of public taxes.

In our daily life the barriers are many and impossible to overcome. 'Just wait a moment, and we will willingly help you', is what we hear. This is fair enough sometimes, but not all of the time. For example, what to do when you are visually impaired, and are to make a withdrawal from a mini-bank? Who is to help you? To whom are you going to hand over your card, and your code? Have you tried to sit for an evening and only stare at the pictures in the news- broadcast? The news is not subtitled for persons with hearing impairments. But of course, in some countries they are kind. That is why they have made a separate little news program lasting 5 minutes for those poor people who cannot hear. Is this inclusion? Is this equality?

This leads me to the simple but still important question: "Why?" Why is it like this, and how come we not get furious and up in arms over this institutionalized discrimination?

## ❑ THE UNDERSTANDING

If we are to understand why, we have to look at the underlying causes, that is, how we - as a group and as individuals - are understood by the society that we are a part of. We have to recognize the premises that have been laid down for how our lives are interpreted and presented by the media, planners, decision-makers and by the man on the street. This is what my next picture will be about: the process of understanding others.

The easiest easy way may be to start with the words we use. Through our language we pass on attitudes that – naturally – also affect our actions. The words simply give meaning to the message.

What words and expressions are used about us? Are they positive or negative? Are they including or stigmatising?

‘Cripple’ – is a concept we perhaps thought was outdated, - but alas, it thrives in the daily papers. The athletic champion Carl Louis from the USA was recently referred to under the following title: “The hero turns cripple”. Here we get a perspective: from an ideal, a ”hero”, to the last limits of defeat, - “the cripple”. The statement affects the one who utters it, and also those who are talked about.

Invalid, deformities, abnormalities, developmental deviations, dysfunctions, sensual defects – all are concepts frequently in use. The characteristics about us are many, and none of them render a positive connotation. The concepts are negatively charged and they create a certain attitude in those who use them, in those who hear them, - and not the least in those who are identified with them.

But even those heavily stigmatising concepts are not enough. A kind of linguistic spice is used to highlight the experience and the formation of the meaning: “Banned to live a life in the utter darkness”, and “chained to the wheelchair” – to mention just a few.

Why is it that a society, that claims, to be enlightened and based on human rights, allows the use of the harshly stigmatising concepts about us? It goes on and on, quite unnoticed, it does not create any arguments, and it does not spark any anger.

Our permanent biological characteristics are looked upon as tragedies, and thereby the myth is created that it is our own bodies that can be blamed for these tragedies. The problem, so to speak, lies within us. But we are our bodies, - our bodies are a permanent part of ourselves. The fact that I cannot walk is not something I can run away from, to put it that way. It is just as certain, and just as constant as the fact, that I am also a man,

and that I have the particular skin colour that I have. It is not the body that is the problem; it is the myth this focus on the pathology and biology has created, - that is our cultural problem.

The core of this understanding is to be found with those who interpret our biological characteristics, - and who have elaborated the doctrine about our lives in terms of tragedies, with the common denominator “serious sufferings”. The core can be found in the culture and tradition of medicine.

You and I, the culture that we are a part of, our society – yes, even we, disabled persons, and everybody else - we let ourselves be indoctrinated. We are regarded as ‘sick’, and therefore we are made ‘ill’. How ill is it really not to be able to walk, see, hear or understand like the majority? Why is it called ill, when in fact we are talking about permanent biological characteristics? Why is it a “serious suffering” to have a biological status for which the medical profession neither has therapeutic nor medical cures? Are we ill? Will we then be both ill and sick when once in a while well fall sick, or are we just permanently ill? When it is called a “serious suffering”, - who then will it be serious for, - and who actually suffers from it?

I do not suffer from not being able to walk. I am in fact quite comfortable with not to be able to walk. I have not walked since youth, and know that I will never be able to walk again. Is there anybody who suffers from me not being able to walk? In that case, it is really serious.

In the medical tradition we are treated and rehabilitated with the focus on the things that our bodies cannot do. This strengthens the understanding that the problem is linked to my body, - and not to attitudes in society or to the design of our surroundings. The body is considered defective, and the goal becomes to correct it – even though no medicine in the world would be able to make me walk. Nor is my goal to be able to walk. My goal is to live my own life. Just as I am able to live it, and not as others think I should live it. I want to live my life together with others, in

the arenas that I have chosen, and not to be confined to the arenas in society where others think I should have access.

- My body, just like yours, is a part of myself. I refuse to consider my own biology as the problem. I refuse to think that it is my own fault that I cannot have equal access to what others take for granted, just because their biology is different from mine.

My problem is NOT my diagnosis, my pains, or my bad circulation of blood. My problem is not that I cannot walk, or that I cannot lift a pint of beer. My problem is not the wheelchair.

My problem is that I have to remain on the sidewalk when my daughter wants me to join her to go to a shop to buy the pair of pants she wants. My problem is that I have to remain thirsty every time I am at a restaurant, because there are no toilet-facilities that I can use. My problem is the attitudes and barriers that are excluding me from the rest of my society.

What is it in our culture that gives society the right to regard me with a defectological eye, and to apply a kind of medical correctness as the answer to questions that concern me, - when for everybody else politics constitute the answer.

Probably in the best of meanings, but certainly without reflecting on the psychological and social consequences, medicine has described clinical findings in the individual as a deviation to what is considered normal. Pathological observations have been, categorized in diagnoses and medical treatment regimes, and labelled us with less than flattering remarks, without the least thought about what kind of signals one gives – which values, so to speak, are fixed to our biological characteristics, how we are, and how we will remain.

This is not meant as an attack on medicine or health professions, but it is an attempt to stir up some deep-rooted traditions, and to help clear up what is medicine, and what is politics. Medical professions today are used as an alibi in social welfare

politics, against the fight for equal rights of disabled persons. If I had time, I could have given you many examples of exactly that. Examples that show that welfare politics and courtroom traditions, are built on the principle that there are people who do not meet the standards. To verify this, we use medical doctors. I travel by bus in London, Berlin and Barcelona. But not in my own country. The busses here are not adapted. But we do not look for a fault in the bus, - rather we demand that a doctor finds a fault with me, and confirms this in a medical report. It is only when the doctor has placed his official signature that I can get some of my transportation needs met. Not together with the others, but segregated, with separate solutions, for “people like you”. With medicine’s authorization, society can continue its discrimination, - and on top of it all, give it a coating of humanism. Maybe this leads to more participation, - but it will never become equal.

#### ■ THE PARALLELS

The third picture has to do with history, and what we have learned from looking at ourselves and at others, in other words it shows a parallel to what I have discussed previously. The motif is again how we in our culture have a long tradition of focusing on the biology of the individual. How we let what we choose to see create the foundation for the perceptions and attitudes of the community at large.

- The way in which we see others will have consequences for the lives of these persons.

In my first school reading book, I could read: “Mother does the dishes and father reads the paper”.

How were women in our own culture regarded 30 years ago, 10 years ago - or now – in our own time? Women were looked upon as the so-called weaker sex. The attitudes towards women were determined by the way in which men viewed women, how men interpreted the qualities of women, and how they let these attitudes have consequences for their lives.

Women were to care for home and children. At that time, a commonly accepted 'truth' was that women did not have the intellectual abilities needed in order to succeed with higher education. It was considered vulgar if women had a professional career. Women were to keep quiet in meetings. Women who both had the desire and talent to communicate with the outer world, for example as writers, were often forced to publish their books under a male pseudonym. There were strict, almost rigid traditions at work, telling people what was appropriate for a woman, - what she was capable of, and what she was allowed to do in a male-dominated culture.

It was the men who interpreted the women, and who passed on the so-called "truth" about their lives. If such suppression is institutionalised over time and generations, then the truths of this male chauvinist culture are reconfirmed as the truths of the society at large. They become normative for politics and society. Even the women themselves, well many at least, were so systematically taught their place and role, that they ended up believing the lies. Some of them even defended the same male chauvinist culture that they themselves were victims of.

But eventually more and more women were waking up. They saw that even if there were biological differences between men and women, this could not be a good enough reason for the suppression to continue. We became more and more willing to critically view what the consequences were of our culturally grounded traditions. We came to understand that the biological differences between women and men were not, in fact, nature's own ranking order, where men were regarded as better than women, or women as better than men. That the truth, on the contrary, is that we are equally worthy, that biological and pathological differences are not abnormal, and that these differences never can legitimise suppression and exclusion.

- Also try to see the parallel to the picture we all have in our heads through the media's coverage of women's lives during the Taliban rule in Afghanistan.

Women clad in burkas against their own will, - stigmatised, made invisible, excluded. In such a cultural and political setting, women – because of their biology – are looked upon as having less value than men. They were excluded from work and education, their place were at the lowest place at the table, or more likely, at another table, in a separate room. They were not to be part of the community; they were to stick to themselves. The reason was their biology.

- Who doesn't remember the white regime in South Africa, and how it treated black people? How blacks were shut out from any equal participation in their own society. How they were not allowed to go to school together with the white people, how they were ordered to use separate entrances, often located at the back of the building, how they were separated to designated seats in public transportation, how they could not do their shopping where they wanted, not visit the restaurants they wanted, how they were not treated as equals.

Do you remember the reasoning behind the politics of apartheid? It was found in the biological characteristics of black South Africans. In the colour of their skin. This biological finding made a whole society systematize segregation, suppression and deprivation of freedom. Just think about it.

Some few years ago the apartheid system was still in function. Today it is over. If the pressure only is strong enough, and does not only come from the stigmatised group them selves, we can end discrimination. It came to an end only when groups other than blacks themselves joined their fight and started to put pressure on the regime, like the international society, and in particular the economically strong West. The external pressure came in the shape of campaigns, sanctions, reactions, and straight talk signalling disgust. Apartheid was not only bad for those directly involved, or for especially interested people. It concerned us all. It threatened us all. It was shameful for us all. But we had to recognize it first.

## ❑ THE RECOGNITION

The last picture is about recognition. The recognition that the differences, the lack of understanding and the parallels in history show us that disabled persons are discriminated against. We are confronting exactly the same mechanisms that trigger attitudes and actions towards us, - treating us as inferiors.

In this instance, it is our biological status that does not match with the established truth about what is accepted as being natural and normal. You cannot walk, so it is your own pathology that restricts your freedom of movement. You cannot see, so it is your problem that you cannot read the information boards in our quiet airports. You cannot hear, so it is your own qualities that decide that you cannot share our non-texted television broadcasts on an equal basis. The focus is directed at the individual, and not at the politics.

- ❑ The very way in which you are looked upon, by those who set the norms, and by those who take the decisions, - it is this that defines your conditions for equality and participation.

Let me quote a man who has dared to speak openly about the lack of equality, and who has given anti-discrimination a face. In one of his books he says <sup>1)</sup>:

- ❑ “We want to be paid a living wage, and to perform work which we are capable of doing, and not work which the Government declares us to be capable of.”
- ❑ “We want to be allowed to live where we want, and not be endorsed out of an area because we were not born there.”
- ❑ “We don’t want to be obliged to live in rented houses which we never can call our own.”
- ❑ “We want to be part of the general population, and not confined to living in our own ghettos.”
- ❑ “We want to be allowed out after eleven o’clock at night and not to be confined to our rooms like little children.”
- ❑ “We want to be allowed to travel in our own country.”

- ❑ “We want a just share in the whole of our country; we want security and a stake in society. Above all, we want equal political rights, because without them our disabilities will be permanent.”

Listen to what he is saying. Compare the substance of his statement with the situation of hundreds of millions of disabled in today’s world. He compared it with disablement, - and he strongly does so even today. He is among the strongest supporters of the disability movement in the world.

- ❑ He ended by stating the following: “I know this sounds revolutionary to the whites in this country.”
- ❑ And even though it sounds quite incredible, it was not disabled people whom Nelson Mandela talked about. It only sounded that way.
- ❑ Have you ever thought about the great similarity there is between the apartheid black people in South Africa lived under, hindering them from equal participation in society – and the conditions disabled persons in the world fight against? The fight against segregation, unnecessary differential treatment, humiliation, degradation and exclusion. The motives were, of course, different, as were the intensity and the brutality they had to face, but the consequences are, nonetheless, quite similar.
- ❑ We do not have equal status to non-disabled people. We do not have the same possibilities for participation. Again, biology is the basis for this discrimination against us.

### WE NEED TO CHANGE OUR FOCUS!

- ❑ There is indeed a great need for a new focus. The discrimination we are facing through out the world, is not a matter of our biology. The true reason lays in culture and politics, in the society, - but also within the fields of rehabilitation it selves.

Therefore rehabilitation can either preserve the myths about us, or call for a shift in paradigm towards disabled persons all over the world?

The distinctions between disablement and impairment are crucial for the understanding of rehabilitation.

The purpose of this World Congress is rethinking rehabilitation. From my perspective, it is important to underline the necessity for a holistic approach to every individual. Every person, despite his or her biological characteristics, is first and foremost a social individual. The concept of rehabilitation must be based on this understanding.

The issue is equality of status, and fighting against discrimination. What is discrimination? In the end, discrimination is differential treatment. Not a positive differential treatment with the intention to create equality, - but, on the contrary, discrimination is an unnecessary differential treatment that leads to segregation instead of inclusion. It is a differential treatment that does not create equal worth and equal status.

Many men were of the opinion, - and many still are, - that women were not discriminated against. The whites in South Africa also strongly held that black people were not discriminated against. "We take care of them" they said. "We give them security since they cannot take care of their own lives." Because those who discriminate cannot see those they discriminate against as equal, they take a patronizing position, taking care of the so - called weak, those who in their opinion are a little helpless, and different.

Those who are exposed to discriminating remarks or actions also get stigmatised, they are labelled – more or less visibly – as "different" and "second-rate". Nobody wants to be second-rate, and it takes courage and power to be different; therefore it is not easy to accept that one is, in fact, being discriminated against.

In addition, if one is discriminated against for a long time, then one also becomes part of the culture where discrimination has been allowed to flourish. History has shown us that many of those who are oppressed, excuse and defend their oppressors. For when society has succeeded in institutionalising discrimination, the discriminated themselves become silenced, humble, and grateful recipients of the goodwill of the discriminating society.

That is why many disabled still call out for more physiotherapy than for freedom – because that is exactly what we are trained to do. But what are we supposed to gain from physiotherapy if we are not given our freedom? As a metaphor I would like to end by stating: We can't waste our time on physiotherapy, - we have to fight against discrimination. And we want you to join forces with us!

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<sup>1)</sup> From **MANDELA**, Nelson (1978) *The Struggle Is My Life*. London, International Defence and Aid for SA. The Rivonia Trial 1963-4. p.174-5.