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Agenda 22 - UN Standard Rules and local disability planning

Picture 1

Thank you

for having invited me to present our experiences about Agenda 22 - a model for implementing the United Nations Standard Rules on the Equalisation of Opportunities for people with disabilities, in short UN Standard Rules.

Some personal data

My name is Ingemar Färm. I am since 15 years, General secretary, now with mostly international tasks, of the Swedish Disability Federation, HSO. I am a member of two disability organisations: The Swedish Association of People with Stomach Diseases due to my own impairment and The Swedish National Society for People with Mental Handicap, the latter one due to my personal and political interest.

Before my job in HSO I was a social investigator in the Swedish Confederation of Trade Unions in 12 years. I have also worked with information and development of the Swedish Social insurance system, been a political advisor to the minister of Family affairs and to the chairman of Stockholm City board. I am 64 years old, married, have 3 children and 7 grandchildren. So, now you know me a little bit.

1. WHAT ARE THE UN STANDARD RULES?

The United Nations adopted the "Standard Rules" in 1993. But it started many years before. In the 1970ies there was an intense discussion about the ultimate disability goals. There was an ideological shift from the individual perspective to the social one. Disability should not be a personal deficiency - it's a relation between the individual and the society. The goal was defined as "A society for all".

UN decided 1981 to be the International Disability Year. In connection with this UN adopted a world action program on disability and announced the following decade as the Disability Decade.

In the middle of the decade there was an evaluation on what had happened. A discussion began to launch a UN Convention on Human Rights for people with disabilities. The proposal on a convention from Italy and Sweden did not reach a majority in the UN General Assembly.

The next step was to work for the best but one solution. It was called "standard rules". The aim of standard rules was to set a moral and political standard for the governments all over the world to implement some universal goals that were related to the overall vision "A society for all". The UN accepted this model and an international working group elaborated what 1993 became labelled as "The UN Standard Rules".

Bengt Lindquist, who 1994 became appointed as the UN rapporteur for the Standard Rules, was one of the members of the working group. He has told me that, while the representatives from the disability movement argued for the strong word "shall", the representatives from the governments argued for the weaker word "ought to". Anyhow the result was rather good. Many countries have after that adopted the rules as a law or guidelines for the political achievements in the disability field for the country.

The Standard Rules contains 22 rules with 5 to 10 sub rules on each. They are formulated as "The government ought to" do this and that. I don't have the time to explain the content of the 22 rules but I will show you one of them as an example:

”Rule 1. Awareness-raising

Germany should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution.

a) Germany should ensure that responsible authorities distribute up-to-date information on available programmes and services to persons with disabilities, their families, professionals in the field and the general public. Information to persons with disabilities should be presented in accessible form.

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d) Germany should ensure that public education programmes reflect in all their aspects the principle of full participation and equality.

2. CIVIL DIALOGUE

We have a long history of open society in Sweden. One of the elements is the right for all people to read everything that is sent to and from or is produced by the politicians and the authorities. Another important element is that the authorities are obliged to ask affected groups of their opinion on different matters before decision.

I will to give you some examples on how the communication between HSO and the political authorities are functioning.

2.1) The right to be heard

The Swedish government produces every year hundreds of reports of which 40 to 50 are of greater general interest for people with disabilities. The government sends these to HSO to ask for our opinion. After having listened to our 43 member organisations the HSO board formulate the opinion of the Swedish disability movement.

The more the proposals from the report affect people with disabilities the more the government listen to our opinion. Some years ago the government should form a proposal on the future organisation of the Swedish education system. The HSO opinion was very important especially about the system for special education and we affected the decision in the parliament. We wanted an inclusive education system.

2.2) Disability representation in co-operation with authorities

HSO demands consequently our right to point out an own expert in all government committees, which work with issues that will affect people with disabilities. Sometimes they listen but not so often as we wish. Today we have representation in about 10 such committees.

Besides that we have co-operative committees or task forces with many state or other central authorities. 2001 the Parliament adopted a national Disability Action Plan, from Patient to Citizen. One of the elements of this plan was to appoint 14 central authorities as Sector Responsible Authorities. It means that they are responsible within their sector for the implementation of the Action plan. In all these authorities there are co-operation committees with HSO in order to make it possible for the af-

affected groups to influence the implementation and to give us a chance to monitor the implementation.

The governments Disability delegation is lead by the minister of social and family affairs and consists moreover of 14 persons from the disability movement suggested by HSO. In the delegation all issues of importance for people with disabilities can be discussed and sometimes they lead to political actions from the government.

2.3) The media

The disability movement is today a strong opinion making force. Articles in media from representatives from the disability movement have a great impact on the politicians. I have many examples both from election campaigns and from the governments launching of different proposals. If we go to the public and are concrete and serious on an issue, which is important for our members the politicians will listen.

2.4) Conclusions

I name these examples to show that civil dialogue means different things. It is about the official structure of communication, it is about relations between politicians and authority officials on the one side and the representatives of the disability movement on the other. And, at least, it is about mutual respect and understanding. We have criticised the government hard but they respect us because they understand that we react in the interest of our members.

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2.5) Civil dialogue in the local arena

In Sweden local authorities are responsible for many areas that concern peoples everyday lives like housing, education, social services, culture and sports, support to vulnerable groups and so on. This makes it extremely important that every local authority has a good planning in order to build such preconditions that people with disabilities get the same possibilities to live good lives as other citizens.

But even if a municipality has a plan, the most important is how it will work in daily life. There are some models.

We have a long experience of co-operation with local authorities on disability matters. In the **acts** on social service, on personal assistance and

on health- and sickness service, it is stated that the authorities **shall** cooperate with the disability organisations. But the organisational form that is most used for this, "the local disability council", which exists in almost every local community, is mostly a rather passive organisation.

Another model, which has been used in some local communities, says:

- Every board or office in the municipality shall send all proposals that will affect the conditions for people with disabilities to the proper organisation and ask them if they have any point of view on the matter.
- The organisations shall have enough time to react so that they can discuss it with affected members.
- If they wish so they also shall have the right to a meeting with the board or office before they decide on the matter.

However we were not satisfied with the possibilities to influence the disability policy in the municipalities. So when the decision came about the UN Standard rules we discussed within HSO how to implement the rules in the local arena.

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3. AGENDA 22

3.1) Background and basic principles

1995 the Swedish Disability Federation started the project Agenda 22 in resemblance with Agenda 21 from the UN environmental conference in Rio. Agenda 21 has a focus on local network action as the best way of promoting the decisions from Rio. We have the same approach in Agenda 22. But the figure "22" stands for the 22 Standard rules.

Agenda 22 is a method of implementation of the UN Standard Rules. The three most important elements in this work are:

- **first** the recognition of the civic rights or human rights as a basic principle for all disability policy work in the local communities
- **second** the recognition of the disability organisations as the legitimate representatives for people with disabilities and their role as experts in the political process and
- **third** the adoption of a method for planning for the implementation of the Standard Rules in the local community. If we take it short:
 - What shall be done?
 - When shall it be done?
 - Who is responsible?
 - How much will it cost?
 - Which is the follow up procedure?

“Agenda 22” is an uncomplicated method on how local authorities can make good disability policy plans, based on the UN Standard Rules. Which - at the same time – makes Agenda 22 a method for the implementation of the rules. Agenda 22 is built on the conviction that **systematic planning is the most effective way to eliminate all the obstacles** people with disabilities meet.

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3.2) Agenda 22 is built on some ideological principles

The most basic of these principles are

- the fact that all people have **equal worth** and must have the same rights and obligations in society,
- the importance of **living up to human rights** as they are described in the United Nations conventions,
- the fact that people are different and have **different needs** of support,

- that support is **not a privilege, it is a human right,**
- that we use **the UN standard Rules definition on handicap.** I quote:
 “The term handicap means the loss or limitation of opportunities to take part in the life of the community on an equal level with others. **Handicap describes the encounter between the people with disabilities and the environment.** The purpose of this term is to emphasise the focus on the shortcomings in the environment and in many organised activities in society, for example information, communication and education, which prevent people with disabilities from participation on equal terms.”
- that **the organisations of people with disabilities must be accepted as experts** on their own matters.

Picture 7

3.3) The 1st part of Agenda 22: Characteristics of a good plan

This part of the Agenda 22 method consists of eleven over-arching factors that must characterise a good plan. I will mention some of them.

A good plan is built on the UN Standard Rules

The 22 Standard Rules can be used as a structure when a plan is drawn up. The very best is to include all rules in the plan. Another way is to use the rules most relevant for the local authority. In Agenda 22 we always recommend the following five rules to be part of the plan:

- Rule 1 Awareness raising
- Rule 5 Accessibility
- Rule 14 Policy making and planning
- Rule 18 Organisations of People with Disabilities
- Rule 19 Personnel Training

A good plan is produced in close co-operation with the local organisations of people with disabilities

It is only the people with disabilities themselves who know how it is to live with disabilities and what kind of support is needed. In a good disability policy plan all needs must be listed and they must be correctly described. The plan must not be a “drawing-board-product”. Therefore it is absolutely necessary that the organisations of people with disabilities play an active and equal role throughout the entire process when a disability policy plan is planned, written, implemented and evaluated. This is more or less exactly what Standard Rule 18 suggests.

All disability aspects should be integrated in general plans and measures – what we call mainstreaming

People with disabilities are citizens like everyone else and therefore their needs must be treated like everyone else's. Which - in the long run means - that disability aspects must be woven into all planning and activities from the very beginning. This is what we call mainstreaming, when disability aspects are natural parts when – for example - a local authority is planning some sort of measure.

Women and children with disabilities should be paid special attention to in the plan.

We know that many women around the world are discriminated against because of their gender. These women with disabilities risk a double discrimination. The same could happen to children with disabilities. For them it is extremely important to get the same opportunities to a good start in life as other children. In a good plan, the needs of these groups must be paid special attention to in order to avoid discrimination.

Picture 8

The local authority must act as a good example.

The local authorities can play an important role by showing what has to be done and why certain values are important. If they neglect the needs of people with disabilities, it officially signals that these peoples needs are not important. Therefore it is indeed necessary that local authorities set good examples.

- They can arrange information campaigns to improve the common knowledge on how it is to live with a disability.
- They can, when purchasing goods or services, demand that the products are accessible for people with disabilities.
- They can when giving financial support to – for example – a cultural event, set up the condition that the organiser must provide certain accessibility to the event.

The future co-operation with the organisations of people with disabilities must be described in the plan.

That is to secure that there will be a future co-operation and how it is going to be organised. If, for example, working groups are formed, informa-

tion is needed in the plan on how they should be composed, how the work should be carried out and under what conditions.

Specific long-term objectives should be written in the plan.

It is extremely important that there are long-term objectives and that they are clearly formulated – good objectives are short and distinct. The objectives should state that people with disabilities shall have the same rights as others. These objectives could very well be shaped from the introductions of each standard rule. For example concerning cultural (Rule 10) the objective could be as follows:

“In our municipality every citizen should be able to participate in the cultural life.”

The measures must be specifically described

In a good plan it must be clearly written

what measures should be taken,

when it is to be done,

which authority holds the responsibility for the implementation and

how the measure should be **financed**.

If the measures are described in these ways the objectives can be reached in a consequent way. And –at the same time – the disability policy plan will be easier to evaluate as it is easy to see what has been done or not during a certain year.

Ways of evaluation and review must be described in the plan

There are lots of policy documents and many of them end up in a book shelter. A good disability policy plan is a living working-method, an instrument used in practice. The best is if the plan is evaluated every year so there is a continuous following up how the plan is carried out.

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3.4) The 2nd part of *Agenda 22*: Equal partners

As already mentioned – the standard rule No 18 states that society should look upon the organisations of people with disabilities as experts in their own areas. I quote:

”Rule 18. Organizations of persons with disabilities

States should recognize the right of the organizations of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognize the advisory role of organizations of persons with disabilities in decision-making on disability matters.

* States should encourage and support economically and in other ways the formation and strengthening of organizations of persons with disabilities, family members and/or advocates. States should recognize that those organizations have a role to play in the development of disability policy.”

The local disability plan should be produced in close co-operation with the organisations of people with disabilities. This means, that representatives from the organisations must take part during the whole process – from planning to the draft version. The base of the work with the plan could be a special working group consisting of equal representatives from the organisations and the local authority. The group can make plans for the work, put together analysis and suggestions and make a draft version of the plan.

The organisations of people with disabilities must also be represented in every working group during the preparatory work.

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3.5). The 3rd part of *Agenda 22* – ways of working – from idea to disability policy plan

A good plan must be built on the parallel between the needs of people with disabilities for public services, and the resources existing at present. When this knowledge is there, it is possible to plan what measures need to be taken. Therefore two different inventories are needed.

Inventory 1

How is the situation today? What resources do the authority has for people with disabilities? How does the authority live up to the UN Standard Rules at present? The first inventory must deal with just this, a survey on how society lives up the UN Standard Rules today. The very best is if this inventory is carried out in “reality” – not in an office of the local authority but through discussions with people who are affected by the activities. At a school for example, representatives from different personnel groups could discuss the most relevant rules for the responsibility of the school, such as rule no 6 Education and rule no 5 Accessibility together with representative from the organisations of people with disabilities and the pupils.

To make such an inventory easier there are a number of questions to every Standard Rule in the end of the material “Agenda 22 – Local authorities”.

Inventory 2

The purpose of this inventory is to find out what kind of public service people with disabilities need. Here we mean that every single organisation of people with disabilities must be given the possibility to contribute by documenting the need of support, services and measures of accessibility for their own groups.

The comparison of the results of the two inventories will give the base for when a concrete suggestion of measures – and a plan - is to be done.

3.6) Experiences and conclusions

HSO has worked intensively with Agenda 22 for about eight years. During this time we have worked on two parallel tracks.

We worked with the local organisations for people with disabilities in order to give them knowledge about the Standard Rules and the Agenda 22. We produced materials and arranged meetings all over the country where we tried to inspire the representatives from the organisations to work for good disability policy plans in each municipality.

At the same time we also tried to influence the municipalities directly. We sent them information about Agenda 22 and we made an offer for information about Agenda 22 to every municipality. In the end we

had visited about 200 out of 289 municipalities, lecturing about Agenda 22.

We know that all our 289 municipalities have not made their disability policy plans exactly according to the Agenda 22-principles. But we know that we have inspired them to **do** plans, and that Agenda 22 **has given them a strategy and a structure** for how a plan can be organised. During our work we found that many municipalities wanted to make a plan, but they did not know how to do it, and especially not how the plan should be constructed. When they adopted the idea to **use the Standard Rules as a structure and to go through rule by rule** to see what had to be done, they found that the work with the plan became much easier.

A common objection was of course that there is no money. This argument we confronted with that a good plan must be realistic - what is possible to carry out. If there is no money, the plan must be done on a long term. Another argument is of course that it is possible to change existing priorities in favour of people with disabilities if they wish to do so. The most important thing is that the society has the knowledge about the need and that there is a systematic planning.

Another very positive thing was that we could highlight the importance of close co-operation with the local organisations of people with disabilities and **that it would help** the municipalities to use the organisations expertise.

Today most of the Swedish municipalities have a disability policy plan and we are proud to say that we partly can give ourselves credit for this and for how the plans are constructed.

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3.7) HSO experiences

When we discussed Agenda 22 at the conference in Linköping, Sweden, April 2001 during the Swedish presidency of the EU we draw some conclusions:

- Systematic planning can speed up the implementation of disability policy reforms.
- The UN Standard Rules can be used as a structure for disability policy planning.

- Disability policy planning must always be carried out in close co-operation with the organisations of people with disabilities.
- The objectives shall be carried out through different measures. These have to be specific and state:
 - *what* has to be done
 - *when* the measures are to be carried out
 - *where the responsibility* for the implementation lies
 - how the measures will be *financed*.
- The disability policy plan must contain descriptions on how and when the planning shall be evaluated and revised.
- Common strategies are needed and the Agenda 22 is a good one. But the Agenda 22 has been developed in a special social structure, the Swedish, and must therefore be adjusted to different countries.
- More information about The Standard Rules is needed as well as special training on how to use the rules within the disability organisations.

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3.8) Agenda 22, a global model for implementing the Standard Rules?

- After proposals from among others the Dutch and the Irish disability councils EDF has decided to form an Agenda 22-network. EDF has also started a European Agenda 22-project.
- The document Agenda 22 in local communities has been translated to 15 languages, most of them Eastern and Central European languages.

Today there is an ongoing work in the UN to elaborate a Convention on the human rights for people with disabilities. When the convention is adopted in some years, I think that Agenda 22 can be a good tool in order to implement and monitor the new convention.

I hope I have convinced you that Agenda 22 is a good, concrete and practical model of implementing the UN Standard rules in the local communities - also in Germany. Once more - thank you for giving me this opportunity to talk about important measures for making the conditions of life more equal among all human beings.