

“NOTHING ABOUT ARTICLE 33.3 UN CRPD WITHOUT US!”

Questionnaire to EDF members

Involvement in National level policy –and decision-making and monitoring the UN CRPD

No one, but persons with disabilities can contribute the best in designing indicators which could measure effectiveness of their participation. The study which will analyze contribution received from EDF members could be useful for the European disability movement in terms of exchanging experiences on good practices and also to discover common struggles and gaps in their National level involvement.

My name is Magdi Birtha.

I work at the Centre for Disability Law and Policy.

This is a research centre in Galway, Ireland.

I do a project on monitoring the UN Convention on the Rights of Persons with Disabilities.

EDF is also part of this project.

I have worked at EDF since February 2012.

I would like to see how countries monitor the implementation of the Convention.

I would like to see how countries involve civil society and in particular persons with disabilities in their work.

The Convention on the Rights of Persons with Disabilities says that persons with disabilities shall be involved in policy-making relating to their lives.

Persons with disabilities shall also be involved in monitoring the implementation of the Convention.

It would be appreciated to receive your answers until **29 June 2012**.

If you have any questions or would like to get further information please do not hesitate to contact me: magdi.birtha@edf-feph.org.

Many thanks for your cooperation.

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Questions

I. Current situation

1. Who represents civil society in policy and decision-making in your country?
Concerning Disability policies there are two disability federations. The Swedish Disability Federation represents 39 disability NGO:s and Equally Unique, the Swedish Federation Human Rights for Persons with Disabilities, representing 5 disability NGO:s. Totally about 50 organizations get some kind of state funding, but it is not indexed to cover inflation and costs, so the value diminishes and more organizations are sharing the same amount of money. Both organizations are represented at the governments disability forum lead by the minister for children and elderly. Our organization has got 8 representatives and Equally Unique has got 2 representatives. A network for youth disability organizations has got 1 representative. The meetings are held about X times a year and they are used for information of policies not for decision making.

The minister responsible for human rights, discrimination and integration is placed under the department of labour market. The responsibility for the CRPD is in the ministry of social affairs.

The Swedish Disability Federation has raised the issue of the role of disability NGO:s several times. The latest time in a letter to the minister responsible for the National Disability Strategy linked to the CRPD. The letter sent 7th of February in Swedish, can be found on this web page. <http://www.hso.se/intressepolitik/Brev-till-regeringen/Skrivelser-till-Regeringen/>

2. Is civil society represented in the Independent mechanism under Article 33.2? If yes, through which organizations?

No. The government have had 3 rapporteurs make suggestions on how to monitor human rights. The first covered the CRPD, the other two overall human rights issues. A governmental proposal is expected later this year. Our organization has criticised the government for not involving the DPO:s regarding when preparing proposals for monitoring. When the convention was ratified the preparations regarding article 33 was not ready and is still not solved.

3. Is the State equipped with an advisory board or similar body? Which organizations are represented there?

Yes. Our organization has got 8 representatives, the federation Equally Unique has got 2 representatives, a network for youth disability NGO:s has 1 representative. (see also the answer to Q1)

4. What is the function of this advisory board?

The only formal document discusses the responsibility within the government. The minister responsible for disability policy is the chair, state secretaries from the ministry of Social affairs (3), ministry of Employment (2), Enterprise (2), Education (2), Justice (1) and Culture (1). The representation from DPO:s should equal the number of representatives from the government (see also the answer to Q1)

5. How do you find the collaboration between the different organizations of people with disabilities? (e.g. exchange of information, joint efforts, number of meetings etc.) Are there any difficulties?

There are always challenges when there are many organisations of different sizes and needs. The system for receiving funding is also criticised because organisations are competing for the a fixed amount in the national budget. Recently we have seen some positive trends when organisations cooperate on very specific issues. One example we are actively working on now is the campaign to change the discrimination act so that it covers lack of accessibility. Many organisations within and outside federations are contributing both financially and with support in other ways.

Involvement in the implementation of Article 33 UN CRPD

6. Were disabled people's organizations asked their opinion regarding the designation or establishment of the Article 33.2 framework to promote, protect and monitor the implementation of the Convention?

The Swedish government asked a special rapporteur to prepare an investigation on how to Promote, protect and monitor the CRPD in 2009. Our written reply from November 2009 can be downloaded <http://www.hso.se/intressepolitik/Remisser/Remissvar-2009/> Civil society organisations, public agencies etc were consulted at hearings and asked to give written statements. The second report about a new structure for protections of human rights, including the CRPD covering all conventions, had a similar procedure. The proposal and our reply can be downloaded in Swedish. It contains strong criticism on the issue of involvement. <http://www.hso.se/intressepolitik/Remisser/Remisser-2010/Slutbetankande-fran-Delegationen-for-manskliga-rattigheter-i-Sverige--Ny-struktur-for-skydd-av-manskliga-rattigheter-SOU-201070/>

Recently the government invited civil society NGO:s to a meeting on a report on UPR – Universal Periodic Review on human rights. It was 1,5 hours meeting and the government spoke for 1 hour and the NGO:s for half an hour. At the meeting we heard that the government is working on a proposal that they hope to present later this year, but it is a political decision. We decided to make a short written statement to the government where we among other things repeated that they should have an institution complying with the Paris Principles.

7. Did they have other proposals? Does the decision comply with their feedback?
We do not know what the government will decide.

8. Do the focal point(s) and coordination mechanism involve disabled people's organisations?

The ministry of Social affairs is the focal point. They tend to forget involvement of the DPO:s When they answered a questionnaire about political rights some years ago, they had finished the answers before remembering to involve us. We made a separate investigation based on the answers from the government.

9. Are they accessible to these organisations (e.g. website, meetings, partnerships, etc)?
Not applicable

10. Do they consult them on a regular base?

The ministry has got meetings as mentioned in Q1, otherwise there are no regular meetings, only ad hoc invitations to hearings etc.

11. Is your organization involved in **policy making** regarding the implementation of CRPD? What does it mean in practice? Through which channels is it happening?

We had an externally financed project called Agenda 50 that produced an alternative report on the CRPD that was sent to the UN. The project involved broad representation from Disability NGO:s. We have produced educational material on the CRPD and have given lectures and held local seminars But we need funding for that kind of work.

Handisam - Swedish Agency for Disability Policy Coordination – is the agency responsible for coordinating disability policies has no formal council with representatives from DPO:s the government has got the meetings mentioned in Q1

12. Is your organization involved in **decision-making**? What does it mean in practice? Through which channels is it happening?

No

13. Is your organization involved in **monitoring** the UN CRPD? What does it mean in practice? Through which channels is it happening?

We have produced an alternative reports, available in English. <http://www.hso.se/Material/Projektet-Manskliga-rattigheter/Publications-in-English/> See also answer to Q11. Recently we applied for a new project where we should be able to make court cases, identifying indicators to monitor the convention and further raise awareness but it was denied because it was not supported by the public administrative bodies.

We have 2 representatives in a project to develop voluntary indicators for local governments, but the indicators will be voluntary self assessment tools and not to be considered monitoring from an independent point of view.

Involvement in monitoring activities

14. Were disabled person's organisations associated in drafting the State report if there was any submitted to the UN CRPD Committee?

Not really. We decided to make an alternative report, see above.

15. If your country has already submitted a report to the UN, did civil society elaborate a shadow report as well? How did they organise this?

We did an alternative report, see above.

16. Do disabled person's organisations have the possibility to develop their own monitoring activities? (e.g. receiving any support to do capacity building or training session etc.)

We lack funding to do monitoring independently of the public or local administration.

Evaluating current involvement

17. In your country what are the main achievements of disabled people's organisations through Article 33 CRPD so far?

The alternative report provided by the project Agenda 50. We will see if the suggestions we have made covering article 33 will be met in the coming proposal from the state. A problem is that the Swedish government has presented a national disability policy strategy for 2011-2016 that they say is linked to the CRPD report. Handisam the public agency responsible for coordination and monitoring is a counselling body the government on disability policies. They are not independent. We have very little influence of the process linked to the strategy. The agency was recently given a task to use web panel with persons with disabilities to ask questions on the strategy without consulting DPO:s about this solutions and without the possibility to appoint representatives from their organisations to give their views on the strategy. <http://www.handisam.se/Om-Handisam/Vad-Handisam-gor-2/Vara-projekt-och-aktiviteter/Regeringsuppdrag/Uppdrag-att-ta-fram-en-undersokningspanel/>

18. Could you provide practical examples to illustrate this (eg. campaign, capacity building, lobby, etc)?

The Alternative report, see link above. If you are referring to influencing one particular issue, the current work on the discrimination act where DPO:s have protested for several weeks in front of the government building every Thursday when the government has their weekly meeting. We have facebook pages, a yearly march organised in several local places for the past 10 years. Campaigning towards the parliament and we are releasing a socioeconomic study on costs and benefits to include accessibility this week. All these actions are supported by several of the Swedish DPO:s

19. What are the problems? How should the State ensure better involvement?

In the letter to the government our organization suggests involvement at an earlier stage in the political processes, before the decisions are made. The organisation has to be consulted on yearly budget review and in the steering committees of the most important public agencies etc. (See the letter referred to on answer to Q1)

II. Ideal situation – how civil society should be involved

1. What should be the key elements of civil society involvement in the implementation of the CRPD?

Involvements of the organisations before the decisions are made. Funding to DPO:s, financial compensation for representatives from the DPO:s in councils Indicators to monitor the CRPD from the citizen perspective, not from the public administration. A monitoring body fulfilling the Paris Principles needs to be established and work with civil society organisations.

2. What are the key factors in achieving **effective** involvement? (e.g. number and type of NGOs involved in the process, transparent communication, well-functioning coordination mechanism, financial support etc.)

Education and building competences, resources – financial support etc, of course transparent communication and active involvement before decisions are made, also allowing DPO:s to set the agenda, representatives in public administration leading positions to have power in decision making.

Involvement and coordination on local, regional and national level is important.

Indicators are important. Our organisation was denied funding to work on identifying different kinds of indicators for monitoring the convention. Structural indicators: measurement tools for the legal and policy framework Process indicators: measurement tools for implementation of human rights, activities, campaigns etc. Performance indicators: measurement tools to follow up the results of initiatives on and individual and collective perspective.

3. What are the key factors in achieving **active** involvement?¹

Working procedures that allow representatives from DPO:s to be actively involved and influence the agenda, take initiatives, accessibility etc. Capacity building, education and resources to coordinate work on local, regional and national level. See also previous answer.

4. What are the prerequisites of **effective** and **active** involvement of civil society in...

- Policy-making:
To be in the right forums before the decisions and where decisions are made.
- Decision-making:
To make sure that representatives have the mandate from DPO:s and competence to make decisions.
- Monitoring of Convention:
Make sure that DPO:s are involved in identifying indicators to reflect citizens with disabilities and that the DPO :s can take part in the whole process when planning, introducing and monitoring the implementation of the CRPD

5. How should the State guarantee representativeness of civil society members?
DPO:s should have the power to select their own representatives.

¹ The concept of describing involvement in ideal case as active and effective was discussed with a number of self-advocates during the development of this questionnaire. It is important to make a difference between active and effective involvement. Active involvement refers to what extend persons with disabilities are involved, how often and at which levels they can participate in meetings etc. Effective involvement considers the results of their collaboration and the direct influence of their participation in policy- and decision-making.

6. How can representativeness be assured? (e.g. involve the same or always different NGOs, who should they represent etc.)

Mandated time for representatives from federations of DPO:s Involvement of representatives from youth organisations.

7. What kind of financial investment would be needed to ensure effective involvement of people with disabilities?

DPO:s funding to work independently, representatives receive full and equal compensation for work, preparation for meetings, travel and accommodation.

8. Do you think that capacity building and empowerment would be necessary conditions of involvement? If yes, in what form it should happen?

Yes. It is important that capacity building works both ways, so that the public sector learns about the organizations from civil society as well.

9. What would guarantee sustainability of the involvement?

Involvement should be standard procedure and on a regular basis for policy- and decisionmaking Important to evaluate the quality and results of involvement to fulfil article 4.3 and 33.3 The need for involvement to secure effective decisions and policies must be promoted and studied.

Background: Questions to Civil society representatives on their involvement

According to **Article 33.3** UN CRPD Civil society, in particular persons with disabilities and their representative organizations shall be involved and participate fully in the monitoring process. **Article 4.3** UN CRPD refers to the importance of involving persons with disabilities in all policy – and decision making processes concerning issues relating to their lives. The **Preamble (o)** also emphasizes that persons with disabilities should be actively involved in decision-making processes, policies and programmes, including those directly concerning them.²

Referring to the paradigm shift and to the slogan “Nothing about us without us!” the effective and active involvement of persons with disabilities should be considered as one of the key elements of successful implementation of the CRPD. Most Member States are still in the process of establishing their Article 33.2 framework to promote, protect and monitor the implementation of the CRPD therefore it is very important to ensure the participation of DPOs from the very first stage. Our knowledge is very limited on what kind of initiatives or

² UN Convention on the Rights of Persons with Disabilities

(<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>)

good practices are taking place in the Member States in order to provide active involvement instead of formal consultations for persons with disabilities.

The aim of the research is to collect qualitative data directly from members of the disability movement on the current National situation and to explore key elements of effective and active involvement.