

## Reply from The Swedish Disability Federation to the questions from special rapporteur on the rights of persons with disabilities Ms Catalina Devandas-Aguilar.

2015-09-15

### The right of persons with disabilities to participate in decision-making - Call for submissions

<http://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/DecisionMaking.aspx>

We have also enclosed answers to a questionnaire from 2012, when there was research done by Magdi BIRTHA connected to a European research project called Dream.

The Special Rapporteur on the rights of persons with disabilities, Ms. Catalina Devandas-Aguilar, is currently preparing a study, to be presented at the 31st session of the Human Rights Council (March 2016), on the *right of persons with disabilities to participate in decision-making*.

The Special Rapporteur welcomes inputs, in **accessible formats**, in English, French or Spanish, from Member States, international and regional organizations, UN agencies, funds and programmes, organizations of and for persons with disabilities, civil society, national human rights institutions and other national independent mechanisms designated or established to monitor the implementation of the Convention on the Rights of Persons with Disabilities, disability or equality Ombudspersons, scholars, research institutions and policy think tanks, private sector businesses and networks, community movements, and private individuals, to provide information about the *right of persons with disabilities to participate in decision-making*.

Submissions should be sent by e-mail to the address [sr.disability@ohchr.org](mailto:sr.disability@ohchr.org) no later than **15 September 2015**. Concise responses are encouraged, inclusive of relevant attachments where available. Kindly indicate if you have any objections with regard to your reply being posted on this website.

#### Specific information request:

**Question 1** Please provide information on the legislative and policy framework in place in your country related to the status, establishment, resourcing, and functioning of representative organizations of persons with disabilities at the national, regional and local levels

There is an ordinance SFS2000:7<sup>1</sup> for government grants to support efforts to achieve full participation and equality in society for people with disabilities. 60 disability organizations at national level have been allocated these grants. The amount of money has stayed the same for many years despite the fact that more organizations are sharing the same amount every year.

2 Please provide information on existing legislation and policies aimed at ensuring that persons with disabilities and their representative organizations, including children with disabilities, are consulted and involved in decision-making processes that directly or indirectly concern them;

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<sup>1</sup> Information in Swedish about the ordinance

<http://www.socialstyrelsen.se/statsbidrag/aktuellastatsbidrag/handikapporganisationer>

There are policies to establish reference groups and to appoint experts to government inquiries. When we have asked representatives about the quality most of them say that we are not participating in the decision making and that we have not got the right prerequisites for it.

Organizations representing parents to children with disabilities are included in the two umbrella organizations and in some cases organizations representing young persons with disabilities are invited. On a regional and local level there are often both youth councils and disability councils. We do not have statistics about how many young persons with disabilities are represented in either of the consultation bodies.

3 Please provide information on any consultative body or mechanism established to consult and engage with representative organizations of persons with disabilities, including information about their composition, criteria for membership (nomination, appointment, election, etc.) and functioning;

The government disability delegation meets four times a year and is chaired by the minister responsible for children, elderly and gender equality from the Ministry of Health and Social Affairs. Our organization has got 8 representatives and another umbrella Equally Unique has got 2 representatives. A network for youth disability organizations has got 1 representative. The meetings are used for information of policies not for decision making. We can nominate our own representatives for the meeting. There are rules from the state to get state financing. Each organization representing persons with disabilities has their own statues with elected boards etc.

There are also 22 "strategic" authorities with a role in the national disability strategy with written instructions to consult with NGO:s representing persons with disabilities, as well as a number of voluntarily established consultations with other authorities. There are consultations at county and municipal level. They are funded locally within each county and municipality, but the funding, functioning and status of advisory boards differ a lot all over the country.

4 Please provide information on the efforts undertaken at national, regional and/or local levels to strengthen the capacity of representative organizations of persons with disabilities, in order to facilitate their participation in legislative, policy and other decision-making processes;

At national level we have not seen any special efforts, the organisations on local and regional level are independent from us. But we get information that there are difficulties on the local level especially for persons with cognitive impairments to participate. In 2014 we approached the Swedish Association of Local Authorities and Regions to ask them to undertake an effort but after consideration and process in their organization they decided it was not given priority.

5 Please explain whether and how persons with disabilities participate in monitoring the implementation of the United Nations Convention on the Rights of Persons with Disabilities (art. 33, para. 3), and in the nomination of experts to the Committee on the Rights of Persons with Disabilities (art. 34, para. 3);

We have not been involved in the monitoring. With project funding the disability movement produced an alternative report in 2011. We have applied for further project funding from the Swedish inheritance Fund to develop indicators on the implementation of the CRPD, but we were denied funding. See also the attached answers to a questionnaire from 2012. The government finances the participation of four participants from NGO:s in the yearly Conference of State Parties to the convention on the rights of persons with disabilities. The question to nominate an expert to the Committee on the Rights of Persons with Disabilities has recently been raised by the government.

6 Please identify the main challenges faced by the diversity of persons with disabilities in participating in mainstream and disability-specific decision-making processes at the national, regional and local levels, including challenges faced by persons who experience multiple discrimination (e.g., on the basis of disability, age, gender, ethnic origin, geographical location).

The Ministry of Health and Social Affairs handles the CRC and CRPD, but the rest of the conventions and responsibility for national human rights is in another ministry – currently the Ministry of Culture. The Ministry of Health and Social Affairs have a tradition to meet only with disability organizations for CRPD and NGO:s involved in the rights of the child for CRC. When the other conventions are handled the whole network of human rights organisations are invited. So we give input to CERD, CEDAW etc. but not vice versa.

Different grounds of discrimination have different protection in the constitution. We have for example tried for years to have the same protection when it comes to hate crimes and harassment as other groups, but it has been denied by governments. The rights based perspective is still not fully achieved. The recommendations from the CRPD committee **urges the State party to ensure that the Convention is properly incorporated into Swedish legislation in order for it to be applicable as Swedish law and also to ensure that the indicators system to design measures to encourage municipalities to monitor implementation.**

The diversity in membership within many organizations representing persons with disabilities could be much better. There have been several projects to increase diversity when it comes to ethnic background and LGBT, but more could be done.

7. Please provide information on the existence of organizations of persons with disabilities in your country, including organizations of children and women with disabilities, as well as their composition and internal decision-making processes and procedures;

There is an organisation representing Forum - Women and Disability in Sweden<sup>2</sup> it works as a network, and we cooperated recently on comment to the CEDAW committee.

Organisations representing young persons with disabilities are sometimes independent and they can apply for funding from The Swedish Agency for Youth and Civil Society.

Each organization has their own statutes. The Swedish disability Federation has existed since 1942 as an umbrella organization. Currently we have 39 member organization representing about 400 000 individual members.

A biannual General Assembly is held where the presidents of each organization decide on priorities and elects our board. There are also several Presidents Meetings each year.

The Board prepares the meetings and draft decisions of the Presidents' Meetings and implements their decisions. The Board also has the power to decide on behalf of the Swedish Disability Federation when the Presidents Meetings not are convened.

The Chairman of the Board is elected by the general assembly, and is also a full member of the Presidents' Meetings.

In all counties and most municipalities there are associations of local disability organisations. They are organised in approximately the same way as Swedish Disability Federation but they are independent and have different compositions of member organisations.

<sup>8</sup> Please identify the main challenges faced by the diversity of persons with disabilities as members of mainstream or disability-specific non-governmental organizations, and in participating in the activities of such organizations, including challenges faced by persons who experience multiple discrimination.

Barriers are often linked to lack of accessibility and awareness. The political parties have few members and very few representatives with disabilities. As we mentioned earlier we could be much better at attracting diversity among members so we can become better at fighting multiple discrimination. One small way of trying to achieve a change is that we are demanding that the responsibility for all human rights treaty bodies should be gathered in the same Ministry, we fight together for the establishment of a NHRI and for establishing synergies and action plans for all recommendations to the state party from different treaty bodies.

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<sup>2</sup> <http://www.kvinnor-funktionshinder.se/>