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| **Memorandum**  |  |
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| 10 September 2015 |
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| **Ministry of Health and Social Affairs** **Sweden** |
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| Social Services Division |
| Lars Nilsson |
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Questionnaire from The Special rapporteur on the rights of persons with disabilities, Ms. Catalina Devandas Aguilar

# 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.

The status, establishment, resourcing and functioning of representative organizations of persons with disabilities are based on:

*The National Action Plan for the Disability Policy (Från patient till medborgare – en nationell handlingsplan för handikappolitiken (prop. 1999/2000:79).*

In the national action plan the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities are quoted and the importance of participation by the Disabled Persons Organisations in planning, implementation and evaluation of support and service is underlined (page 31 ff).

*The Ordinance (2000:7) on State Subsidy to Disabled Persons Organizations.*

A state subsidy is distributed to the Disabled Persons Organizations on a yearly basis with the purpose of providing improved financial conditions for advocacy work for persons with disabilities in the society. The subsidy is 182 742 000 SEK, in 2015.

*The Government Delegation on Disability*

The Minister for Children the Elderly and Gender Equality meets on a regular basis with representatives of the disability movement for strategic consultations on policy content and development.
The representatives are proposed by the Disabled Persons Organizations and appointed by a decision by the Government.

*The Strategy for the Implementation of Disability Policy, 2011–2016.*

22 state agencies have been tasked with implementing Swedish disability policy on the basis of the Swedish Strategy on Implementing the Disability Policy. The greater part of these agencies have established consultations with the disabled persons organisations and several are planning on embarking on the process of establishing such consultations. Municipalities and county councils report that they have established some form of consultation with the disability organisations.

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

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*Regulation on cooperation with civil society in swedish legislation*

The Health and Medical Services Act (1982:763) The Social Services Act (2001:453), The Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments (LSS), Local Government Legislation (1991:900) and the Planning and Building Act (2010:900), specify consultation with persons using services and civil society as being part of the planning process for the provision of the respective public service.

The government has decided on greater emphasis on children in LSS as of 1 January 2011. When actions relate to children, the best interests of the child must in particular be taken into account. When assistance is to be given to a child, the child must receive relevant information and be given the opportunity to put forward his or her opinions. Significance shall be attached to the opinions of the child depending on his or her age and level of maturity.

The National Board of Health and Welfare’s regulations and general guidelines on management systems for systematic quality, SOSFS 2011:9 (Ledningssystem för systematiskt kvalitetsarbete), requires that providers of services to persons with disabilities have consultations with other providers, authorities, associations and organisations.

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

The Minister for Children the Elderly and Gender Equality meets representatives of the disability movement for strategic consultations on policy content and development. The representatives are suggested by the Disabled Persons Organisations and appointed by a decision by the Government.

The Swedish Agency for Participation has organized a Disability Council (Funktionshindersråd), composed of members appointed by the Swedish umbrella organizations (The Swedish Disability Federation, Equally Unique and The Network of Young Persons for Accessibility.

The Disability Council has made a joint agreement with the Swedish Agency for Participation which defines its framework. The agreement is based on the Council of Europe Code, European Code for civil society organizations participation in decision making.

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The Swedish Agency for Participation’s yearly surveys also show that the form for the consultative process varies. For example, in 2014 all of the 18 respondent regional authorities in the transport sector report having some type of consultation with disability organisations.

Consultative bodies comprised of representatives from Disabled Persons Organizations are found in the municipalities and in the county councils. Consultations are carried out on different levels (e.g. municipal/county boards, committees, working groups, service providers, etc).

# 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.

The Minister for Children the Elderly and gender equality meets representatives of the disability movement for strategic consultations on policy content and development. The representatives are suggested by the Disabled Persons Organisations and appointed by a formal decision by the Government.

The Ordinance (2000:7) State Subsidy to Disabled Persons Organisations is a state subsidy distributed to the Disabled Persons Organisations on a yearly basis with the purpose of providing improved financial conditions for advocacy work to improve the situation for persons with disabilities in the society. The subsidy is 182 742 000 SEK, in 2015.

The Government has decided on a budget on 500 000 SEK with the aim to enable Swedish Disabled Persons Organisations to attend the Meeting of The State Parties to the UN CRPD. The Government support covers travel expenses, accomodation and other expenses for the representatives of the organizations.

A guidance document for consultation with the Disabled Persons Organisations for public agencies, (”To consult with the Disabled Persons Organisations”), has been developed and is available on the web-site of Swedish Agency for Particpation.

The website www.overenskommelse.se was developed by the government, non-profit organisations in the social sphere and the Swedish Association of Local Authorities and Regions with the purpose to strengthen non-profit organisations’ influence in decision-making processes and to increase diversity of providers and suppliers of health care and social care. It includes information and tools to support cooperation.

To support consumers’ influence in standardization work, a part of the government funding allocated to standardization, is used to finance the involvement of representatives from organisations representing user interests. Involvement of the Disabled Persons Organisations in standardization activities can facilitate the uptake of accessibility requirements and recommendations in society. The funding is administered by the Swedish Standardisation Federation’s SKA Council (consumer and employee council).

# 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).

The Government is presently planning for a strategy on Human Rights in Sweden. An important part of the strategy is a proposal for an independent national institution, with the task to protect and promote human rights according to the Principles relating to the Status of National Institutions for the Promotion and Protection of Human Rights (A/RES/48/134).

The Government has assigned The Swedish Agency for Participation to follow-up progress in relation to i.a. the goals and progress in the national disability policy. In the follow up, The Swedish Agency for Participation consults with representatives from the Disabled Persons Organisations.

The national panel, Rivkraft, participates in the monitoring of the national disability policy. To date the panel is comprised of approximately 1 800 volunteer participants from 16 years of age. The panel responds to three to five on-line surveys per year.

Information gained in the follow-up process is resported to the Government.

The nomination procedure to the UN Committee on the Rights for Persons with Disabilities, is based on a proposal coordinated within the Government offices. The Ministry of Health and Social Affairs (Focal point for the disability policy) has the task to coordinate the proposal and also to represent Sweden at the annual meeting of the State Parties to the UNCRPD.

The Swedish delegation to the meeting of the State Parties (where the decision on experts to the Committee is passed), is composed by i.a. representatives from The Swedish Disability Federation, Equally Unique and the Network of Young Persons for Accessibility.

# Please identify the main challenges faced by the diversity of persons with disabilities in participating in mainstreaming 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).

Firstly, The Government, State Agencies, county councils and municipalities need to improve their ability to aquire knowledge and experience from persons with disabilities who are the beneficiaries of the measurses provided.

Secondly, their is a need for developing the support to the state agencies, municipalities and county councils in their efforts to consult with civil society and involve them in processes and decision making.

Thirdly, continuing efforts are needed to involve the Disabled Persons Organisations in the information- and decisionmaking processes within the Government Offices.

Finally, as the Government announced in its report in June 2015 to the Human Rights Committee within the UPR-process, it intends to propose the establishment of an independent national institution, with the task to protect and promote human rights in accordance with the Paris Principles.