

Sundbyberg 2018-07-12

Submission to the 20th Session of the Committee on the Rights of Persons with Disabilities

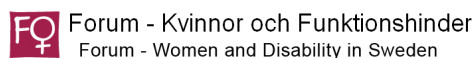
List of issues prior to reporting for Sweden

Submitting organization: The Swedish Disability Rights Federation

The Swedish Disability Rights Federation¹ is a national umbrella for organisations of persons with disabilities founded in 1942, with **41 member organisations** representing approximately 400 000 persons.



Contributing organisations²:



Contact for this submission

Mia Ahlgren

The Swedish Disability Rights Federation

Box 1386, 17227 Sundbyberg, Sweden

Phone: +46 8 546 40400

Mobile: +46 70 268 5222

Email mia.ahlgren@funktionsratt.se

Web <http://funktionsratt.se>

Twitter http://twitter.com/funkratt_se

Introduction

By all measures, Sweden is one of the richest countries in the world. However, since the first constructive dialogue with the UN CRPD committee (2014), budgetary cutbacks in disability rights to independent living, in direct violation of the human rights-based approach, have dominated the policy agenda.

Sweden has still not established a National Human Rights Institution. It remains almost impossible to claim redress for violations of human rights, due to fragmented accountability³ between service providers, public agencies, local, regional and national government and lack of legal aid to claim rights in courts.

Ad hoc assignments, enquiries and reports have had no positive impact on human rights bearers' daily life. Inequality persists or has increased in the most central aspects of a person's life: level of income, education, health, social protection, work and living conditions, including access to transport and built environment.

Currently there is no strategy for a systematic and coordinated approach to data collection and indicators for monitoring of rights in the CRPD. The strategy for disability policy 2011-2016 was followed by a new goal for disability policy linked to human rights, approved in the Parliament in November 2017. In March 2018 the government commissioned an enquiry to draft a new system for targets and evaluation of policy. However, the enquiry will not propose new legislation or review how well existing laws comply with the CRPD. The draft report should be ready in January 2019.

Recommendations from the CRPD Committee in 2014 concerning incorporation of the Convention into Swedish law, personal assistance, supported decision making and forced treatment were repeated by the Commissioner of Human Rights of the European Council⁴ in 2017. Other UN treaty bodies have also raised concerns⁵.

Executive summary

This submission consists of brief updates on Sweden's compliance with Convention, including follow up on recommendations from 2014⁶ and suggested review questions for the simplified reporting procedure.

Proposed questions for List of Issues prior to reporting

Articles 1-4 General principles and obligations

The recommendations to incorporate the CRPD in Swedish law and to review national indicators to cover all areas of the Convention in all municipalities have not been addressed. The Parliament has decided to incorporate the Convention on the Rights of the Child⁷. Meanwhile, a study⁸ commissioned by the government shows that the CRPD is neither used for decisions in public agencies nor in courts.

The human rights-based approach is missing in government, public administration and the judiciary system. This is evident in the government's deliberate portrayal of personal assistance as a "cost problem" to legitimize cutbacks⁹, in court judgements regarding the right to personal assistance and in how the Swedish Social Insurance Agency chooses to interpret these judgements.

There is no systematic approach to implement and mainstream the Convention when preparing new legislation and when enforcing existing legislation.

Research and development linked to universal design and accessibility is not evaluated to match definitions in the Convention.

Neither the public sector¹⁰ nor individuals¹¹ have sufficient knowledge or understanding of who is accountable and how the system works for claiming redress and remedies for violation of rights.

Organisations of persons with disabilities, OPD:s, meet with the Ministry of Health and Social Affairs¹², but are seldom actively involved in actual decision-making processes, nor in the delegation for national implementation of Agenda 2030.

Proposed Questions articles 1 to 4

1. Provide detailed data on progress and outcomes to:
 - a) ensure recognition of concepts under article 2 and principles under article 3 in laws, regulations and policies in both public and private sectors, including the systems for support in education, employment and social security.
 - b) ensure that official government reports, bills, legislation and policies are harmonised with the Convention and adequately funded, at the national, regional and local levels, for both new issues and evaluation of enforcement and effectiveness of existing ones.
 - c) adopt concrete national action plans and programmes with clear benchmarks, baselines and indicators to ensure progressive realization and hinder retrogressive

measures in the implementation of economic, social and cultural human rights, addressing differences in local and regional government.

- d) ensure that promotion of Universal Design, including participation of users with disabilities in the process, is mainstreamed in research, development and standardization with the goal of achieving accessibility, availability and affordability of mainstream products and services including new technologies.

2. Provide detailed data on development of funding and support to OPD:s to ensure:

- a) active participation of persons with disability of all ages in all aspects of CRPD implementation and monitoring on national, regional and local level;
- b) promotion of leadership opportunities and participation of persons with disability across all areas of political, social, economic and cultural life;
- c) active involvement in developing indicators for sustainable development goals and standards,
- d) access to timely and appropriate individual advocacy support and legal aid.

Article 5 Equality and non-discrimination

The government has not addressed the recommendations to define reasonable accommodation in legislation that cover all areas of society nor examined the structure for intersectional discrimination.

Since May 2018, the provision on “inadequate accessibility” in the Discrimination Act (2008:567) is extended to cover enterprises with less than 10 employees. However most of these small enterprises rent their facilities and the owner of the building is not responsible under the Discrimination Act.

The provision on “inadequate accessibility” in the Discrimination Act applies to existing regulations which don’t protect all persons with disabilities. The Act does not cover reasonable accommodation in all areas of society. Housing, law enforcement and the judiciary system are examples of exemptions.

The Discrimination Act, requires employers and providers of schools to take active measures to prevent discrimination. The active measures cannot be enforced without better sanctions and guidelines that specify what measures apply to prevent “inadequate accessibility”.

Very few discrimination cases are considered or taken to court by the Equality Ombudsman¹³. Lack of redress results in fewer reports of discrimination, hence statistics on complaints¹⁴ (also important for SDG 10.3.1) do not accurately reflect perceived discrimination.

Proposed Questions article 5

3. Provide detailed data on progress and outcomes to ensure that

- a) anti-discriminatory law and framework encompasses all forms of discrimination, including discrimination by association to persons with disabilities, perceived disabilities, past and future disabilities, and multiple and intersectional discrimination.
- b) denial of reasonable accommodation is explicitly defined and recognized in legislation as a prohibited form of discrimination in all areas of society, including housing and the public sector.
- c) funding of independent mechanisms and legal aid to prevent, investigate and sanction all forms of discrimination against persons with disabilities, and ensure adequate compensation for discrimination to persons with disabilities.
- d) policies and programmes, including affirmative action measures, are allocated with sufficient financial and human resources, to achieve *de facto* equality for persons with disabilities.

4. Provide updated data on claims of disability discrimination, disaggregated by sex, age, identified barriers, the sector in which discrimination occurred and data on remedies, cases brought to court, settlements, sanctions or compensation.

Article 6 Women with disabilities

There has been no progress on outcomes of measures to address recommendations related to gender equality¹⁵ and violence¹⁶ to women with disabilities.

There is still lack of accurate, intersectional, disaggregated data, including data on sexual and reproductive health rights of girls with disabilities¹⁷ and sexual abuse.

Proposed questions article 6

5. Provide information on measures and data on progress concerning legislation, administration and policy to:

- a) eliminate all forms of violence and sexual abuse against women and girls with disability
- b) ensure accessible shelters, recourse to justice and redress for victims of violence and abuse

- c) ensure sexual and reproductive health rights of women and girls with disabilities

Article 7 Children with disabilities

The government has initiated official reports related to recommendations from 2014 but they have not resulted in positive outcomes.

A government official report about violence related to psychiatric treatment of children covers many recommendations, but there is no proposal to prohibit use of straps and seclusion without consent¹⁸

Children aged 10-17 with experience of mental ill-health¹⁹ increased by 100 percent 2006-2016²⁰.

Children have been severely affected by the cutbacks in personal assistance, resulting in fewer possibilities to live independently²¹.

Children with autism are forced into homes for care or residence (HVB) for children and young people with reference to The Care of Young Persons (Special Provisions) Act 1990:272 (LVU)²².

Proposed questions article 7

6. Provide data on progress on the development of legislation, policies and professional training of staff to ensure the rights of children with disabilities to accessible forms of communication.

7. Provide data on progress to improve mental health and abolish all forms of force in relation to children with disabilities.

Article 8 Awareness raising

A government assignment to the Swedish Agency of Participation, the Ombudsman for children and the Equality Ombudsman to raise awareness and disseminate recommendations from the Committee, has not resulted in measurable data on progress. No sustainable strategy for campaigns and education been developed. There is no evidence of the project's long-term effects.

The proposal from OPD:s to actively involve organisations in translation of the first four general comments from the Committee was accepted by the Agency for Participation, however priority was not given to other proposals from OPD:s to identify gaps in curricula for relevant professional training, and to provide a long-term strategy to deepen understanding of the CRPD.

There is no reference to the CRPD in mainstream public enquires, policies and programs, indicating low awareness and understanding of

the human rights-based approach in government, parliament, judiciary, public and private sector²³.

Proposed questions article 8

8. Provide detailed data on progress and outcomes of measures in relation to the committee's recommendations from 2014.

9. Provide information about strategy to ensure a human rights-based approach in public and private sector, law enforcement, education, social security, design of built environment, transport and ICT

Article 9 Accessibility

There has been no progress on the recommendation to remove existing barriers in the built environment. Coordinated enforcement and assessment of the effectiveness of legislation, monitoring systems and complaints for new and existing built environments remains inadequate.

A survey²⁴ concerning municipalities' removal of easily eliminated obstacles²⁵ shows that cases can be still pending 10 years after the complaint was made.

Accessibility was introduced in legislation for the built environment in 1967²⁶, but new building is still approved that create accessibility barriers. There is no coordinated monitoring system if the municipality does not act on reports of violations and gaps persist in accessibility legislation and standards that include all impairments.

The recommendation about systematic use of accessibility requirements in procurement contracts has not been addressed. In the national public procurement strategy, accessibility requirements are presented as a possibility rather than "shall requirements" as stated in the law²⁷.

Accountability for public transport is fragmented, with lack of national follow-up on outcomes. Most reports are based on local data from passengers, not from disabled persons who have been excluded from travelling.

The proposed implementation of the European Web Accessibility Directive contained misunderstandings of general accessibility measures (ex-ante) and individual right to access through reasonable accommodation (ex-nunc) as explained in general comment 2 and 6.

Proposed questions article 9

10. Provide an update of measures to ensure that legislation, standards and policies cover all disabilities, including persons with chronic illnesses, allergies and cognitive disabilities.

11. Provide updated data disaggregated for municipalities and/or regions on outcomes, complaint mechanisms and progress of legislation policies and programs to monitor and ensure universal design and full accessibility regarding

- a) new buildings and built environment
- b) removal of existing barriers in the built environment
- c) public transport
- d) information and communication, including ICT and online services

12. Provide updated data on outcomes of measures to ensure systematic implementation of accessibility requirements in all public procurement contracts, including support, use and development of accessibility standards for infrastructure, built environment and ICT.

13. Provide detailed information on progress of a strategy with actions, timelines and budget for universal design and removal of existing barriers for accessibility, including funding of research, innovation, professional training and certification schemes.

Article 10 Right to life

There has been no policy revision addressing the recommendation on suicide prevention, despite higher risks for suicide due to worsening mental health for young persons²⁸.

In 2018 a man died having been strapped in belt for 42 hours when he was in a facility for psychiatric care.²⁹

Higher mortality due to diabetes and stroke is found among persons with mental ill health³⁰. Higher mortality due to heart attack and cancer are found among persons with intellectual disabilities living in group homes³¹.

Proposed questions article 10

14. Provide data (disaggregated by disability, gender, age and cause of death) on outcomes of measures to follow up legislation and education after reports of inequality in access to health services, higher mortality and incidents of death in care homes or medical facilities.

Article 11 Situations of risks and humanitarian emergencies

The recommendation to ensure fully accessible and inclusive disaster risk reduction has not been addressed.

Lack of strategy, coordination and accountability in public agencies and public service broadcasting in providing accessible information. A

recent example is the lack of information in sign language reported in connection with the terrorist attack in Stockholm in April 2017³².

Proposed questions article 11

15. Provide detailed information on mainstreaming accessibility in regulations and communication strategies to all stakeholders, including persons with cognitive disabilities and intersectional perspectives, for emergency situations and risk reduction.

Article 12 Equal recognition before the law

The recommendation on supported decision-making has not been addressed.

Organizations representing persons with intellectual disabilities report that members are assigned guardian or trustees against their will and decisions are taken without access to supported decision-making.

Government actions³³ after critique from the Swedish National Audit Office regarding monitoring of legal guardians and trustees, does not include supported decision-making.

Legal aid to ensure support for individual claims of rights of persons with cognitive disabilities is not provided.

Proposed questions article 12

16. Provide data on progress to establish the right to supported decision-making in legislation, complaints mechanisms and monitoring of abuse of the right to equal recognition before the law.

17. Provide data on funding to ensure legal aid and support for persons with intellectual disabilities to fulfill article 12.

Article 13 Access to justice

The right to trial and legal representation is being hindered by lack of sufficient funding for legal aid programs for individuals claiming human rights violations, including persons with disabilities, as reported by civil society to the Human Rights Council.³⁴

The absence of the right to legal aid within the administrative court system³⁵, results in very few decisions in favor of the individual³⁶.

There is continuing lack of knowledge and education for court employees on the CRPD³⁷.

There is no monitoring of legislative implementation of the right to understand and be understood³⁸ and its impact on court decisions. Research³⁹ shows that judges do not believe accounts of victims of

sexual abuse if they are aware that the victim has a diagnosis such as neuropsychiatric disorder.

Persons with neuropsychiatric disorder diagnosis are no longer accepted for professional police training, due to outsourcing of recruitment and training of police officers.

Proposed questions article 13

18 Provide detailed data on outcome of measures to

- a) address the lack of access to justice for persons with cognitive disabilities
- b) ensure effective remedies in relation to human rights violations,
- c) increase the use of the CRPD in the judiciary system,
- d) increase the number of participants and improve training about the rights in the convention for professionals within the judiciary system

19 Provide data on provisions and financing of legal aid for persons with disabilities and the outcome of court judgement and decisions on claims.

Article 14 Liberty and security of the person

Separate submission from Civil Right Defenders⁴⁰

Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment

Separate submission from Civil Right Defenders⁴¹

Article 16 Freedom from exploitation, violence and abuse

Despite reports⁴² of invisibility, high risks of exploitation, violence and abuse, even prejudice in courts⁴³ there are no reports on progress.

Current legislation does not protect persons with disabilities from hate crimes and harassment on an equal basis. While broadening protection to include other groups at risk in society, the government has not responded to alerts from OPD:s to the situation for persons with disabilities.

Proposed questions article 16

20. Provide detailed intersectional data on progress and outcomes of measures to

- a) monitor and reduce risk for exploitation, violence and abuse
- b) ensure equal protection in legislation from hate crime and harassment

Article 17 Protecting the integrity of the person

Forced institutionalisation of children with autism⁴⁴, as well as forced use of seclusion, strapping belts and electro convulsive treatment (ECT) (see CRD submission for article 15) are examples of violations.

Proposed questions article 17

21. Provide disaggregated data for gender and age on progress and outcomes of measures taken to protect the physical and mental integrity of persons with disability from treatment without the prior, free, full and informed consent of the person, on equal basis with others.

Article 18 Liberty of movement and nationality

New migration legislation includes special requirements for employment that may have negative impact on the chances for migrants with disabilities to get a residence permit or be reunited with family⁴⁵.

Migrants with disabilities lack support, assistive technology, accessible housing and training during the establishment process in Sweden⁴⁶.

Proposed questions article 18

22. Provide data on effects of legislation, policies and other measures to ensure rights of migrants with disabilities.

Article 19 Living independently and being included in the community

Despite strong national finances, the government took measures to cut costs for personal assistance in 2016⁴⁷. Cutbacks, court judgements and interpretations of the Swedish law by the Social Insurance Agency have caused a severe crisis with about 1500 persons losing state-funded personal assistance since 2015⁴⁸. The Government has decided on temporary changes in legislation, but there is no strategy to repair damage that's been done. There is no strategy to address the right to live independently in the community, including lack of housing, lower standard of living and significant differences in the support across the country. Furthermore, the changes in the interpretation of the law, have had an adverse effect on children and families⁴⁹.

In 2017, 12 700 decisions⁵⁰ granting individual supports were not implemented by municipalities. The number has increased since 2013⁵¹.

Proposed questions article 19

23. Provide detailed information on progress since 2014 with disaggregated data for gender, age and municipality with respect to

- a) all forms of support to persons with disabilities, including personal assistance, that enables persons to live independently and actively participate in society on an equal basis
- b) choosing where to live and access to housing
- c) income levels

24. Provide information on training and education about the right to live independently for staff in public agencies, public and private service providers and professionals within the judiciary system.

25. Provide data on outcomes of complaints to public agencies, court decisions and interpretation in guidelines from the Social Insurance Agency and municipalities, including compensation or sanctions.

Article 20 Personal mobility

The responsibility for transport and assistive technology is spread among regional public agencies and private service providers. Systems for payment for public transport and policies for support to personal mobility vary around the country. Seamless, independent and spontaneous travel is impossible, as there is no national coordination of assistance for transport.

Changes in rules for financial support for car adaptations, have increased costs for individuals. Several municipalities have added fees for disability parking permits. Reports from around the country of malfunction in procured special personal transport service (including reports of sexual abuse)⁵².

Proposed question article 20

26. Provide updated disaggregated data on progress and outcomes, including differences in regions, to
- a) ensure personal mobility for persons with disabilities with access to appropriate assistance across regions and transport modes
 - b) monitor legislation for transport, including procurement of vehicles and service providers, system for grievance mechanisms, redress, use of sanctions and public awareness about who is accountable.

Article 21 Freedom of expression and opinion, and access to information

Barriers in the Constitution⁵³ prevent allowing accessibility requirements on content distributed via internet. There are also exemptions in the Constitution for several discrimination grounds about hate speech, but disability is not included. The proposal to implement EU directive for digital public administration doesn't include accessibility⁵⁴. The right to alternative and augmented communication is not clearly expressed in any law.

Proposed questions article 21

27. Provide data on progress and outcomes of measures to remove barriers in all legislation, including the Constitution, to ensure
- a) access to information, including web technology and access to alternative and augmented communication,

- b) protection from hate speech against persons with disabilities

Article 22 Respect for privacy

Standard assessment tools for personal assistance (such as timing showers and toilet visits) violate privacy and personal integrity.⁵⁵

There is no right to internet access for persons living in group homes. Many persons with disabilities are dependent on others to access information, that often lead to involuntary sharing of private data. But OPD:s have not been involved in the government's work to update digital privacy regulations⁵⁶.

Proposed questions article 22

28. Provide data on outcomes of legislation and other measures, to ensure the right to privacy for all persons with disabilities, including accessible information about these rights.

Article 23 Respect for home and the family

Adverse effects for children with disabilities have been reported after cutbacks in personal assistance⁵⁷. There is no data about effects for parents with disabilities.

Persons living in group homes can seldom choose where and with whom they want to live.

Proposed questions article 23

29. Provide data and progress on impact of legislation and policies with respect to geographical differences, to ensure the respect for home and the family, including

- a) the right to choose with where you want to live
- b) effects for parents with disabilities
- c) effects for children with disabilities

Article 24 Education

There is no strategic plan for attaining inclusive education in line with the convention. The Government appointed a School Commission that proposed funding related to socio-economic needs but no funding related to support for pupils with disabilities nor any mention of universal design for learning.

Studies⁵⁸ show that many children (nearly 50 percent of whom have cognitive disabilities) stay at home due to lack of support, stigma and mental health issues.

Legislation is restricting the potential of children with disabilities to get support for higher grades than E. Children with dyslexia are not allowed to use assistive technology in national exams.

Despite existing laws that allow all children the freedom to choose school, children with disabilities do not have this option⁵⁹, as privately owned schools may still deny admission to pupils with disabilities in certain cases.

Proposed questions article 24

30. Provide disability disaggregated data on outcomes of legislation and other measures to ensure the right to education on equal basis in the whole country, including the right to choose school, to reach the highest potential grade and the right to assistive technology.

31. Provide detailed information on a strategy and action plan for inclusive education in line with general comment 4, with trained staff and adequate resources allocated to support students with disabilities.

Article 25 Health

Significant gaps remain in equal access to health⁶⁰, with higher mortality for persons with disabilities as described under article 10. Despite several initiatives mental ill-health is increasing, even for young persons⁶¹.

There are many concerns about the situation and lack of data regarding sexual and reproductive health rights, especially concerning girls with intellectual disabilities⁶².

Health legislation in Sweden is not based on rights, so for example the right to information and participation cannot be exercised. The system for filing complaints has become more complex, fragmented and less coordinated, making it harder to get equal access to health services and to achieve systemic change.

Proposed questions article 25

32. Provide disability disaggregated data (including hearing impairments, speech impairments and cognitive disabilities as well as intersectional perspectives) covering all regions, on measures with outcomes to ensure that all health services and treatments, of whatever nature, particularly sexual and reproductive health services, are provided to people with disability, on the basis of their prior, free and informed consent.

33. Provide detailed data on progress to ensure knowledge about the rights of persons with disabilities in public and private health care on all levels for each county and municipality, including the right to full participation, accessible information and complaint mechanisms.

34. Provide information on strategies to ensure follow up on progress with data on access to health care, indicators for differences in mortality and an analysis of effects.

Article 26 Habilitation and rehabilitation

There are significant differences between the 21 health regions concerning rehabilitation, when it comes to the provision of services and the quality of services related to endurance and intensity. There is also lack of staff with the competence required to meet the different needs of persons with disabilities.

Proposed questions article 26

35. Provide disaggregated regional and national data on access and outcomes of rehabilitation and habilitation, within adequate time and with intensity and endurance in accordance with research and national recommendations for different disabilities, to enable maximum independence, full inclusion and participation in all aspects of life

Article 27 Work and employment

Unemployment rates remain high for persons with disabilities. The government has targets for gender balance and diversity among state employees in terms of numbers and promotions. However, persons with disabilities have only a program offering limited work internships, not real jobs.

A small increase in the budget for financial support to employers and supported employment has resulted in higher compensation per person, but not to more persons in employment.

The government has asked the Public Agency for Employment to investigate consequences of the use of the term "people with reduced capacities or limitations" in accordance with the recommendation from the Committee, however changes in the wording are to be proposed only "if necessary" ⁶³.

Deaf, hard of hearing and deafblind persons have limited access to working life due to lack of access to interpreting services.⁶⁴

Proposed questions article 27

36. Provide data on a strategy and outcomes of all measures to
- a) increase employment of persons with disabilities, including young persons and to develop a strategy to solve gender inequality.
 - b) ensure equal labour rights and inclusion for persons with disabilities, including persons in daily activities and sheltered workshops
 - c) provide adequate interpreting services to ensure access to work

37. Please update the Committee on the progress of recommendation 50 in relation to the status of the term persons with reduced work capacity.

Article 28 Adequate standard of living and social protection

95.000 women and 74.000 men are financially dependent on a “guaranty benefit” that is less than half of the minimum wage⁶⁵. As the state guarantee level is related to a person’s assets, it is difficult to own or inherit anything without risking losing benefits.

Persons with disabilities often have costs for rent, transportation, rehabilitation, dental care, medicine and other expenses that exceed their income. Rent for housing in group homes is often higher than the average rent for comparable housing, with no less expensive options available. There are significant geographical differences in the level of support provided by municipalities.

Proposed questions article 28

38. Provide progress of gender/age disaggregated comparative data for income and costs for living for persons with disabilities who cannot work and relate it to the development of state financing of benefits.

Article 29 Participation in political and public life

There have been some improvements in access to voting, but large gaps in political participation remain for persons with disabilities⁶⁶. Projects have been initiated by civil society organisations to increase the number of voters with disabilities.

Proposed questions article 29

39. Provide updated gender/age disaggregated data on progress and measures to increase political participation in and between elections, political parties, government and public administration, including supported decision-making.

Article 30 Participation in cultural life, recreation, leisure and sport

There are significant gaps for young persons with disabilities participation in culture life, recreation and sports related to lack of accessibility and negative attitudes⁶⁷.

Civil society organisations have reported that cutbacks in personal assistance has negatively affected access for children and adults to participation in leisure activities.

Proposed question article 30

40. Provide updated disaggregated data for regions, age and disability on participation in cultural life, recreation, leisure and sport

41. Provide updated data on outcomes of accessibility requirements in state funding of culture and an analysis of measures for progress.

Article 31 Statistics and data collection

There has been no dialogue on human rights indicators and how to improve statistics and data collection with OPD:s.

The Agency for Participation report⁶⁸ for disability policy in 2017 provides information about inequality in relation to health, education, work and income. In most areas there is no comparison with earlier years. It is not clear when the data was updated. There is no access to raw data to compare situation in different parts of the country. There is no follow up on accessibility. The report concludes that targets are missing in most areas. It also states that the human rights awareness has increased, but no data is provided to support this statement.

Statistics Sweden's report on national indicators for Sustainable Development Goals⁶⁹ does not provide disability disaggregated data. At a seminar in 2018 the Agency claimed that it isn't possible to provide disaggregated data for disability.

Proposed questions article 31

42. Provide detailed data on progress on recommendation 56 from concluding observations, including information on active involvement of organisations of persons with disabilities in decisions regarding statistics.

Article 32 International cooperation

There is no information on progress regarding the recommendation to spread the twin track approach in international cooperation.

Proposed questions article 32

43. Provide updated data on measures to ensure that disability, including disaggregated data, and the social dimension of sustainability is mainstreamed into strategies and plans to implement and monitor national the 2030 Agenda for Sustainable Development.

44. Provide details about how the Government supports OPD:s to promote the leadership of people with disability in disability inclusive development.

Article 33 National implementation and monitoring

There is still no concrete proposal to establish a National Human Rights Institution, NHRI, with resources to fulfil article 33.2. Sweden accepted several recommendations to establish a NHRI, at the Universal Periodic Review (2015)⁷⁰. The Department of Culture⁷¹ has initiated work to draft proposals concerning the establishment of the institution to be presented 2018.

In the initial State Party report 2011, the government made references to an official report about the implementation of article 33, but the government closed the dossier in 2017, without dialogue with OPD:s or consideration of concerns and recommendations about the focal point and coordination in the government. The role and effectiveness of the Agency for Participation has been under review.⁷²

Proposed questions article 33

45. Provide information on progress and outcome of measures to fully implement and ensure:

- a) mainstreaming of the human rights-based approach for the focal point and coordination in the government
- b) full mandate, independence and resources for a national human rights institution
- c) resources and support to OPD:s to participate in all aspects of implementation and monitoring, on national, regional and local level to fulfil article 33.3.

Explanatory notes

The Swedish Disability Rights Federation

¹ The Swedish Disability Rights Federation, founded in 1942, is an active member of European Disability Forum and the coordinating organisation for CRPD reporting within the network of Human rights within the United Nations Association of Sweden.

<http://funktionsratt.se/om-oss/in-english/>

Contributing organisations

² Civil Right Defenders,

Equally Unique

DHR

Forum Women and Disability

Independent Living Institute

The Swedish Association for Sexuality Education (RFSU)

The Swedish Foundation for Human Rights

The Swedish Youth federation of mobility impaired

The United Nations Association of Sweden

Introduction / Executive summary

³ Raoul Wallenberg Institute, Round table report A Swedish National Human Rights Institution, 2016: "The lack of clarity regarding what institution to turn to when your rights have been violated leads to a situation where victims do not know where to turn to for redress. As it is today the expectations of being heard and redressed will depend on what entity will handle the case."

<http://rwi.lu.se/publications/roundtable-report-swedish-national-human-rights-institution-exploring-models-options-roundtable-report-organised-raoul-wallenberg-institute-human-rights-humanitarian-law-lund/>

⁴ Commissioner of Human Rights for Council of Europe report following visit to Sweden, 2018 <https://rm.coe.int/commdh-2018-4-report-on-the-visit-to-sweden-from-2-to-6-october-2017-b/16807893f8>

⁵ Committee on Economic, Social and Cultural Rights, Concluding observations on report of Sweden, 2016, includes recommendations to address unemployment (24), financial cuts in personal assistance (30), mental health and forced treatment (44)

<http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=4slQ6QSmlBEDzFEovLCuW0cqPuV%2fF2dyNH9MACbemkb%2blRCiKI28wF7FQEsVHiK%2fO3NGOJkFwgNmQui%2fk9xAhNmtQ7T%2bYVLsUKHEjwIwNe%2fc2QmlkU5cUJn7P%2bMISrjf>

Human Rights Council, Concluding observations on seventh periodic report of Sweden (ICCPR), 2016, includes recommendation to strengthen measures to access employment, education, health care, justice and governmental services, without any discrimination (13) and ensure training of law enforcement officers about mental disabilities to avoid use of violence.

⁶ Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Sweden, 2014
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fSWE%2fCO%2f1&Lang=en

Articles 1-4

⁷ Swedish government article, Convention on the Rights of the Child will become Swedish law, June 2018

<https://www.government.se/government-policy/childrens-rights/>

⁸ Patrik Bremdahl, Maria Grahn Farley, Jane Reichel, Uppsala University, Principen om fördragskonform tolkning i förhållande till Sveriges konventionsåtaganden om mänskliga rättigheter, 2018 A report commissioned by the ministry of Culture regarding the use of human rights treaties in courts and public agencies for remedial interpretation.

⁹ Niklas Altermark, Department of Political Science, Lund University, 2017, article about how the government tried to legitimize austerity measures targeting personal assistance for people with disabilities

<http://journals.lub.lu.se/index.php/svt/article/view/17444>

¹⁰ Patrik Bremdahl, Maria Grahn Farley, Jane Reichel, Uppsala University, Principen om fördragskonform tolkning i förhållande till Sveriges konventionsåtaganden om mänskliga rättigheter, 2018 A report commissioned by the ministry of Culture regarding the use of human rights treaties in courts and public agencies for remedial interpretation.

¹¹ Raoul Wallenberg Institute, Round table report A Swedish National Human Rights Institution, 2016 "The lack of clarity regarding what institution to turn to when your rights have been violated leads to a situation where victims do not know where to turn to for redress. As it is today the expectations of being heard and redressed will depend on what entity will handle the case."

<http://rwi.lu.se/publications/roundtable-report-swedish-national-human-rights-institution-exploring-models-options-roundtable-report-organised-raoul-wallenberg-institute-human-rights-humanitarian-law-lund/>

¹² The Minister for Children, the Elderly and Gender Equality is responsible for Disability policy and the CRPD in the government, The Ministry of Health and Social Affairs is the focal point for the CRPD.

<https://www.government.se/government-of-sweden/ministry-of-health-and-social-affairs/lena-hallengren/cv-lena-hallengren/>

Articles 5 - 9

¹³ Commissioner of Human Rights for the Council of Europe, Report after visiting Sweden 2-6 October 2017, <https://rm.coe.int/commdh-2018-4-report-on-the-visit-to-sweden-from-2-to-6-october-2017-b/16807893f8>

¹⁴ Strategic litigation and action to justice for victims of discrimination, presentation by Lena Svenaeus, former Equality Ombudsman, Lunds university, 2018 <https://lagensomverktyg.se/wp-content/uploads/sites/4/2018/05/LenaSvenaeus.pdf>

¹⁵ Swedish Agency for Participation, Gender analysis report, 2016 <http://www.mfd.se/stod-och-verktyg/publikationer/rapporter/rapporter-2016/en-jamstalldhetsanalys-av-levnadsvillkor-och-delaktighetsmojligheter/>

¹⁶ Swedish Agency for Participation, Report on violence, 2017, <http://www.mfd.se/stod-och-verktyg/publikationer/rapporter/rapporter-2017/mans-vald-mot-kvinnor-med-funktionsnedsattning/>

¹⁷ Civil society submission to Catalina Devandas on Sexual and Reproductive Health, 2017 http://funktionsratt.se/wp-content/uploads/2017/02/SpecialRapporter_SRHRDisability_BN170512_Send.pdf

¹⁸ Ombudsman for Children, position on Swedish Government Official Report about Use of force in psychiatric treatment for children, May 2018 <https://www.barnombudsmannen.se/barnombudsmannen/vart-arbete/nya-remissvar/2018/05/for-barnets-basta/>

¹⁹ The term mental ill-health is used in Sweden in policy and research, "the term mental ill-health encompasses both the various psychiatric problems for which there are clinical diagnoses, as well as minor and moderate mental afflictions that, while falling short of diagnostic criteria, still can have a negative impact on the individual."

<https://www.diva-portal.org/smash/get/diva2:1158446/FULLTEXT01.pdf>

²⁰ The National Board of Health and Welfare report on mental health for children and young persons, December 2017,

<http://www.socialstyrelsen.se/nyheter/2017/kraftigokningavpsykisk-ohalsahosbarnochungavuxna>

²¹ The National Board of Health and Welfare report on consequences of judgements related to parts of the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) (1993:387) and The Social Services Act (2001:453), December 2017

<https://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20773/2017-12-19.pdf>

²² Submission by the Autism and Asperger Association to the National Board of Institutional Care quoting data from public enquiries about children with autism in HVB, 2018

<https://medlem.foreningssupport.se/rfa/uploads/nedladningsbara%20filer/SiSskrivelsemars2018.pdf> A survey has shown lack of

competence about autism of service providers for HVB

https://www.autism.se/granskning_hvb

²³ The Swedish Agency for Youth and Civil Society Report Fokus 17, mentions that municipalities are not aware of the CRPD

https://www.mucf.se/sites/default/files/publikationer_uploads/ung

[a-funktionsnedsattning-etablering-arbets-och_samhallsliv-fokus17-del2.pdf](#)

²⁴ Zotéeva, Anna, Lagen som verktyg, Study on how Swedish Municipalities handling of easily removed obstacles, 2018, <https://lagensomverktyg.se/2018/undersokning-kommunerna-brister-i-sin-tillsyn-av-enkelt-avhjalpta-hinder/>

²⁵ National Board of housing, building and planning, Regulation BFS 2003:19, English translation https://www.boverket.se/globalassets/publikationer/dokument/2008/hin1_removal_of_easily_eliminated_obstacles_bfs_2003_19.pdf

²⁶ National Board of Housing Building and Planning, Swedish Building Norm 1967, for download <https://www.boverket.se/sv/lag--ratt/aldre-lagar-regler--handbocker/aldre-regler-om-byggande/sbn-fran-1968-till-1989/>

²⁷ The National Agency for Public Procurement, presents the law as a possibility to make accessibility requirement not as in due EU directive article 42: "For all procurement which is intended for use by natural persons, whether general public or staff of the contracting authority, the technical specifications shall, except in duly justified cases, be drawn up so as to take into account accessibility criteria for persons with disabilities or design for all users."

<https://www.upphandlingsmyndigheten.se/hallbarhet/socialt-ansvarsfull-upphandling/Tillganglighet-och-samtliga-anvanda-res-behov/>

Articles 10 - 20

²⁸ National Center for suicide research and prevention of mental ill-health, Karolinska Institutet, 2018, <https://ki.se/en/nasp/startpage>

²⁹ SVT, Public Service TV, investigating deaths linked to use of belts in psychiatric care, April 2018,

<https://www.svt.se/nyheter/granskning/ug/det-har-ar-baltning>

³⁰ The term mental ill-health is used in Sweden in policy and research, "the term mental ill-health encompasses both the various psychiatric problems for which there are clinical diagnoses, as well as minor and moderate mental afflictions that, while falling short of diagnostic criteria, still can have a negative impact on the individual."

<https://www.diva-portal.org/smash/get/diva2:1158446/FULLTEXT01.pdf>

³¹ National Board of Health and Welfare, reports in 2011, 2013, 2016

³² Swedish organisations representing deaf and hard of hearing, statement about emergency information, April 2017

<http://www.sdr.org/component/k2/item/1646-allvarliga-brister-pa-information-i-kris-drabbar-dova-och-teckensprakiga-hart?tmpl=component&print=1>

³³³³ Government statement about improved monitoring of legal guardians and other forms of substitute decision-making, May 2018

<https://www.regeringen.se/pressmeddelanden/2018/05/atgarder-for-en-battre-tillsyn-pa-området-for-gode-man-och-forvaltare/>

³⁴ Swedish Disability Rights Federation and Independent Living Institute submission on article 13 to the Human Rights Council, April 2017 for download from

<http://www.ohchr.org/EN/Issues/Disability/Pages/RighttoAccessJusticeArticle13.aspx>

³⁵ Sebastian Wejedal, Doctoral Thesis, The right to counsel about access to justice, 2017 states that absence of legal aid give rise to Access Barriers, since most individual parties are forced to proceed pro se in disputes against highly skilled adversaries, versus state and municipal agencies. In view of this asymmetry, it is asserted that self-represented litigants are not always guaranteed effective access to a court/a fair trial. <https://gupea.ub.gu.se/handle/2077/53582>

³⁶ The Swedish National Association for persons with disabilities (FUB) in the county of Stockholm, report on court judgements concerning LSS in the administrative court in the county of Stockholm, 2016. The report shows that only 5-15 percent of the judgements (excluding cases of personal assistance) were in favour of the individual. In 22 of the 36 favourable judgements the individual had paid for their own legal counsel. The survey also shows significant differences within the municipalities <http://fubstockholmslan.se/wp-content/uploads/2018/03/Hur-f%C3%A5r-man-r%C3%A4tt-i-LSS-m%C3%A5l.pdf>

³⁷ Summary of surveys, 2012 -2016 made by the administration for the Swedish Courts. The public agency was one of 22 strategic public agencies for the disability policy 2011-2016. The agency made a yearly survey about the right to accommodation and information, the CRPD and discrimination among staff. Very few judges answered the survey, and those who did showed low awareness about the CRPD and rights. Legal staff at lower level also got low results, and there is no training about the CRPD, only a voluntary e-learning module about “needs of persons with disabilities” that was ready in 2014. The agency has stopped making surveys as there is no longer any assignment from the government.

³⁸ Directive 2012/29/EU on rights of victims of crime, chapter 2, article 3, considered by the government to be implemented in Swedish law <https://eur-lex.europa.eu/legal-content/en/TXT/PDF/?uri=CELEX:32012L0029&from=EN>

³⁹ Lainpelto, K., Isaksson, J., Lindblad, F. Does Knowledge about a Neuropsychiatric Disorder Influence Evaluation of Child Sexual Abuse Allegations? Journal of Child Sexual Abuse, 35:3., p 276-292, 2016

⁴⁰ See submission from Civil Right Defenders to the 20th session of the CRPD committee, including questions about 1) detention without consent in medical or care facilities on the basis of actual or perceived disability and 2) lack of support in municipalities for persons in forensic

psychiatric care that have been declared ready to be discharged by their doctors.

⁴¹ See submission from Civil Right Defenders to the 20th session of the CRPD committee including questions about 1) gender and forced actions, 2) inhuman or degrading treatment and the use of coercive measures in facilities providing care, medical treatment or similar institutions, and 3) human rights indicators to monitor treatment of persons in psychiatric care.

⁴² Several reports, the latest: Swedish Agency for Participation, Report on violence, 2017, <http://www.mfd.se/stod-och-verktyg/publikationer/rapporter/rapporter-2017/mans-vald-mot-kvinnor-med-funktionsnedsattning/>

⁴³ Lainpelto, K., Isaksson, J., Lindblad, F. Does Knowledge about a Neuropsychiatric Disorder Influence Evaluation of Child Sexual Abuse Allegations? *Journal of Child Sexual Abuse*, 35:3., p 276-292, 2016

⁴⁴ Submission by the Autism and Asperger Association to the National Board of Institutional Care quoting data from public enquiries about children with autism in HVB, 2018

<https://medlem.foreningssupport.se/rfa/uploads/nedladningsbara%20filer/SiSskrivelsemars2018.pdf> A survey has shown lack of

competence about autism of service providers for HVB

https://www.autism.se/granskning_hvb

⁴⁵ Swedish Agency for Participation, Persons with disabilities in the asylumseeking process, 2016 <http://www.mfd.se/stod-och-verktyg/publikationer/rapporter/rapporter-2017/personer-med-funktionsnedsattning-i-asyl--och-etableringsprocessen/>

⁴⁶ Independent Living Institute, Disabled Refugees welcome, 2018 <https://disabledrefugeeswelcome.se/2018/03/disabled-refugees-welcome-interview-study-results/>

⁴⁷ Swedish Disability Rights Federation, Letter to the CRPD committee about State Party measures regarding article 19, October 2016,

<http://funktionsratt.se/wp-content/uploads/2018/05/LetterCRPDcommittee20161018.pdf>

⁴⁸ Assistanskoll, June 2018 statistics based on data from The Swedish Social Insurance Agency <https://assistanskoll.se/TEMA-statistik-om-personlig-assistans.html>

⁴⁹ The National Board of Health and Welfare report on consequences of judgements related to parts of the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) (1993:387) and The Social Services Act (2001:453), December 2017

<https://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20773/2017-12-19.pdf>

⁵⁰ The Health and Social Care Inspectorate (IVO), report about decisions that were not executed within 3 months according to the Social Service Act (SoL) and the Law regulating Support and Service to Persons with certain functional disabilities (LSS), 2017 <https://www.ivo.se/om-ivo/statistik/ej-verkstallda-beslut/>

⁵¹ The Swedish National Audit Office has started an investigation that should be ready in February 2019, as the number of decisions granting support has increased with 44 percent from 2013 to 2016

<https://www.riksrevisionen.se/nu-granskas/pagaende-granskningar/statens-atgarder-nar-rattighetslagar-inte-foljs.html>

⁵² Swedish Government Official Report, SOU2018:58 on Special personal travel, June 2018

https://www.regeringen.se/49ef76/contentassets/8e36a1b782cb4da7b71b3719bcb5423b/sou_2018_58_till-webb.pdf

Articles 21 -30

⁵³ Swedish Agency for Participation, Report on consequences related to EU proposal for a Accessibility Directive, 2016 raises issues about the Fundamental Law on Freedom of Expression that is part of the Constitution. The Law has been changed to allow accessibility requirements for certain online distributed media, but several gaps for webbased media and content exist.

<http://www.mfd.se/globalassets/dokument/publikationer/rapporter/2016/konsekvensutredning-om-tillganglighetsdirektivet/2016-25-konsekvensutredning-tillganglighetsdirektivet.pdf>

⁵⁴ The Swedish Disability Rights Federation, reply to a Government Official Report about digital public administration, 2018

<https://www.regeringen.se/498cdb/contentassets/3732d18b71124cd8bd60b49d6a629f62/funktionsratt-sverige.pdf>

⁵⁵ Lill Hultman, Live life! Young peoples' experience of living with personal assistance and social workers' experiences of handling LSS assessments from a Child perspective, thesis Karolinska institutet, 2018

https://openarchive.ki.se/xmlui/bitstream/handle/10616/46286/The_sis_Lill_Hultman.pdf?sequence=3&isAllowed=y

⁵⁶ The Swedish Disability Rights Federation, Position on a Government Official report called Reboot of digital administration, SOU 2017:114

http://funktionsratt.se/wp-content/uploads/2018/02/Remissvar-Reboot-omstart-digital-f%C3%B6rvaltning-2017_114.pdf

⁵⁷ The National Board of Health and Welfare report on consequences of judgements related to parts of the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) (1993:387) and The Social Services Act (2001:453), December 2017

<https://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20773/2017-12-19.pdf>

⁵⁸ The Autism and Asperger association, School enquiry, 2018

https://www.autism.se/skolenkat_2018

⁵⁹ Swedish National Agency for Education, Report on accessible learning environments, 2016 https://www.skolverket.se/om-skolverket/publikationer/visa-enskild-publikation?_xurl_=http%3A%2F%2Fwww5.skolverket.se%2Fwtpub%2Fws%2Fskolbok%2Fwpubext%2Ftrycksak%2FRecord%3Fk%3D3686

⁶⁰ Public Health Authority, Final report disability strategy, 2016.
<https://www.folkhalsomyndigheten.se/globalassets/livsvillkor-levnadsvanor/funktionsnedsattning/slutrapport-funktionshindringsuppdraget-2011-2016.pdf>

⁶¹ The National Board of Health and Welfare report on mental health for children and young persons, December 2017,
<http://www.socialstyrelsen.se/nyheter/2017/kraftigokningavpsykiskohalsahosbarnochungavuxna>

⁶² Civil society submission to Catalina Devandas on Sexual and Reproductive Health, 2017 http://funktionsratt.se/wp-content/uploads/2017/02/SpecialRapporter_SRHRDisability_BN170512_Send.pdf

⁶³ Government article about assignment to the Swedish Agency for Employment about "reduced work capacity", December 2017
<https://www.regeringen.se/pressmeddelanden/2017/12/arbetsformedlingen-ska-se-over-termen-nedsatt-arbetsformaga/>

⁶⁴ A coordinated interpreting service, SOU 2011:83 – Proposals from 2011 in a government official report to centralise and coordinate interpreting services providing more independence and quality for users have not been implemented.

<https://www.regeringen.se/rattsliga-dokument/statens-offentliga-utredningar/2011/12/sou-201183/> Instead, in June 2018, the government refinanced the old inefficient system, without involving OPD:s in this decision.

<https://hrf.se/regeringen-slangertolkmiljoner-sjon-hard-kritik-franhorsel-och-dovorganisationer/>

⁶⁵ Swedish Agency for Social Security, information on disability benefit, 2018

<https://www.forsakringskassan.se/privatpers/funktionsnedsattning/aktivitetsersattning-och-sjukersattning/>

⁶⁶ Swedish Government Official Reports about Democracy, Låt fler forma framtiden, SOU2016:5 <https://www.regeringen.se/rattsliga-dokument/statens-offentliga-utredningar/2016/01/sou-20165/>

⁶⁷ The Swedish Agency for Youth and Civil Society Report Fokus 17,
https://www.mucof.se/sites/default/files/publikationer_uploads/unga-funktionsnedsattning-etablering-arbets-och_samhallsiv-fokus17-del2.pdf

Articles 31-33

⁶⁸ Swedish Agency for Participation, Report 2018:2, 2018

<http://www.mfd.se/globalassets/dokument/publikationer/rapporter/2018/2018-2-uppfoljningsrapport-2017.pdf>

⁶⁹ Statistics Sweden, Statistical Follow-up of the Agenda 2030 for Sustainable Development, 2017,

https://www.scb.se/contentassets/cc84f7debf404250a146e1204ea589b0/mi1303_2017a01_br_x41br1701eng.pdf

⁷⁰ UPR-info.org, <https://www.upr-info.org/en/review/Sweden>

⁷¹ The government strategy for human rights, 2016, mentions the Government Official Report 2009:36 about promoting, protecting and monitoring compliance with the Convention, but it does not specifically relate to article 33 of the CRPD in the proposal to the Parliament to establish an NHRI. Since then an enquiry has started.

<https://www.government.se/4ab459/contentassets/08bcf332d33e40908f918f0cd29a13ae/a-strategy-for-national-efforts-with-human-rights>

⁷² The Agency for Public Administration, report 2016:18 analysis of the Swedish Agency for Participation, 2016

<http://www.statskontoret.se/globalassets/publikationer/2016/201618.pdf>