Second Alternative report on the implementation of the UN Convention on the Rights of Persons with Disabilities in Sweden

Joint Civil Society report submitted by the Swedish Disability Rights Federation for the 30th CRPD committee session March 2024



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# List of abbreviations

OPD - Organizations of Persons with Disabilities

PWD - Persons with disabilities

#### **Public Agencies**

BoV - The Swedish National Board of Housing, Building and Planning

DO - Equality Ombudsman

FHM - The Public Health Authority

FK - Swedish Social Insurance Agency

ISF - The Swedish Social Insurance Inspectorate

IVO - The Health and Social Care Inspectorate

MFD - The Swedish Agency for Participation

SCB - Statistics Sweden

SIDA - The Swedish International Development Cooperation Agency

SoS - The National Board for Health and Welfare

SPSM - The National Agency for Special Needs Education and Schools

#### Legislation

LSS - Act Concerning Support and Service for Persons with Certain Functional Impairments

SoL - The Social Services Act

# Introduction

The Swedish Disability Rights Federation, established in 1942, is the national umbrella for 52 organisations of persons with disabilities in Sweden, and the coordinator for this alternative report.

The alternative report has been prepared by a diverse group of representatives for human rights organisations within civil society in Sweden, primarily organisations of persons with disabilities. The content builds on the report "Respect for Rights?" - a collaborative effort to provide constructive recommendations from right bearers to national duty bearers to implement the whole Convention on the Rights of Persons with Disabilities, CRPD. 110 Civil Society Organisations endorsed the report conducted in 2019. This current report is updated taking into account recent development and the state party report to answer List of Issues prior to Reporting.

# **Executive summary**

Despite being a wealthy country with a history of disability inclusion, Sweden fails to fulfil its obligations under the CRPD. Civil Society Organisations jointly report that the rights of persons with disabilities are at a standstill or even regressing, but politicians seem to be stuck in the image of Sweden as a pioneering country for disability rights. This false perception hinders the implementation of the human rights approach in law and policy.

UN recommendations for implementing the CRPD are mostly ignored, and legislative alignment with the convention is mostly coming from the EU, not from national initiatives.

The disability policy strategy 2021–2031 lacks concrete political reforms, measurable targets, and coordination across ministries. Despite the Swedish government emphasizing focus on integrating the disability perspective into more political and societal areas, the coordination remains with the Ministry of Social Affairs. Public agencies, without political power, are asked to set their own goals.

The paradigm shift to the Human Rights Approach has not been realised and regression is noted in several areas. Even before the economic downturn, the share of GDP represented by the budget for disability and sickness benefits has decreased over decades.

The result is constant cutbacks and stricter practices in assessing the right to different benefits, lack of inclusion in the education system, employment policy and increased risk for poverty. Self-determination has been set aside. There are significant differences across the country, and finally no action plan for systematic removal of barriers for accessibility.

Until the CRPD is fully incorporated in legislation, policy, and decisions in authorities and courts, we will not see any real change regarding the current situation. Due to the lack of systematic work with UN recommendations and concrete political actions to implement the CRPD, we see a need for clear and time-bound demands on our government. We hope that the committee will request the Swedish government to report back within a year about some measures, for example:

- Urgently initiate an independent gap analysis of Swedish law and practice so that measures can be taken to incorporate the rights under the convention into Swedish law with effective access to remedies to enforce these rights.
- Develop an action plan with clear targets and indicators to implement the CRPD and recommendations from the committee in the whole country with funded, effective and meaningful active involvement of OPD:s.
- Strengthen the implementation with more focal points in the government and on regional level with a stronger coordination mechanism in the government that includes OPD:s in decisionmaking and inclusive budgeting.

#### Other urgent recommendations include:

- Amending the Committee Regulation so that all new legislation aligns with the convention.
- Create a legal basis and sustainable funding for OPD:s meaningful and effective involvement in decision-making and monitoring of the CRPD.
- Establish an independent complaint mechanism and revise the legal aid system to ensure enforcement of the rights and access to justice.

# Articles 1-4 Purpose, general principles and obligations

1 The translation of the convention to Swedish does not distinguish between impairment (funktionsnedsättning) and disability (funktionshinder). Universal design is translated as if it was an end result and not a process. The term handicap, not disability, is still used, for example in the ordinance related to funding for organizations of persons with disabilities<sup>2</sup>.

2 The Convention is not used as a basis for decisions in government, courts and public agencies<sup>3</sup>.

3 No dialogue or initiative has been taken to incorporate the CRPD in national legislation, not even to initiate a review on the legal status of the CRPD. Many inquiries were conducted to analyse legal implementation and practice of the rights of the child before the decision to incorporate CRC <sup>4</sup>.

4 One example of the gaps in legislation is the fact that the government amended legal protection from hate speech and hate crimes to include transgender in 2018.<sup>5</sup> No action has been taken to ensure the same legal protection for persons with disabilities. Statistics<sup>6</sup> and review of legislation related to hate speech and hate crimes exclude disability analysis.<sup>7</sup>

5 There is no mechanism in the government or parliament ensuring that new legislation and policies are in line with the CRPD.8

6 The government "Strategy for systematic follow up of Disability Policy 2021 – 2031" has no measurable targets or political reforms, instead it is related to an overarching goal decided by the parliament in

<sup>5</sup> Prop2017/18:59 and CSO statement on need for protection from hatecrimes, September 2020.

<sup>&</sup>lt;sup>1</sup> CRPD official translation to Swedish

<sup>&</sup>lt;sup>2</sup> Ordinance SFS 2000:7

<sup>&</sup>lt;sup>3</sup> Grahn-Farley et al Uppsala University "<u>Principen om fördragskonform tolkning – förhållande till Sveriges konventionsåtaganden om mänskliga rättigheter</u>", 2017.

<sup>&</sup>lt;sup>4</sup> Dir 2013:35 p.4

<sup>&</sup>lt;sup>6</sup> The Swedish National Council for Crime Prevention (Brå), "Polisanmälda hatbrott 2020 - En sammanställning av de ärenden som hatbrottsmarkerats av polisen", 2020, p. 27

<sup>&</sup>lt;sup>7</sup> Independent Living Institute, ILI <u>2023</u>

<sup>&</sup>lt;sup>8</sup> SOU 2010:70 section 3.2.6 p.155

<sup>&</sup>lt;sup>9</sup>Government strategy for systematic follow up of Disability Policy 2021-2031

2017<sup>10</sup>. Public agencies have until 2026 to propose their own targets for an action plan.

7 The government did not take into account several proposals from the government inquiry about political will<sup>11</sup> in the preparatory work for strategy, nor the proposals from OPD:s for a disability rights committee<sup>12</sup> and concrete actions.

8 The first formal government meeting with OPD:s about CRPD committee recommendations from 2014 was held in 2018<sup>13</sup>.

9 Realization of economic, social, and cultural rights in relation to article 4.2 is regressing instead of progressing. The budget for disability and sickness benefits as part of GDP that has decreased for decades<sup>14</sup> contributing to fast increase of the risk for poverty among persons with disabilities in Sweden compared to the rest of the EU.<sup>15</sup> 56 percent of municipalities estimate that they can meet individual needs<sup>16</sup>.

10 Organizations representing persons with disabilities are often asked for referrals but have no formal role related to structured decision-making to implement the CRPD nor to the interdepartmental working group. There are meetings four times a year with the government, but they are not related to systematic implementation of CRPD.

11 State funding for 68 OPD:s has decreased taking into account that five more organizations share the same amount since 2015 without compensation for inflation<sup>17</sup> and higher costs for salaries<sup>18</sup>.

<sup>12</sup>Swedish Disability Rights Federation reply to consultation, October 2019

<sup>&</sup>lt;sup>10</sup> Government goal for Disability policy from Bill 2016/17:188

<sup>&</sup>lt;sup>11</sup> SOU 2019:23 Para 2 p.16

<sup>&</sup>lt;sup>13</sup> Swedish Disability Rights Federation proposals to the government about <u>action plan</u> to <u>implement recommendations</u> 2014, reply about <u>priority recommendations</u>

<u>December 2017</u> and <u>additional comment after meeting about recommendations in</u>

<u>February 2018</u>.

<sup>&</sup>lt;sup>14</sup> FK <u>Social Insurance in Figures 2023</u> Image on page 16 show decrease of costs and page 17 show comparison with other European countries with lower part for disability compared to other nordic countries.

<sup>&</sup>lt;sup>15</sup> <u>European Disability Forum Human Rights Report Issue 4</u> on Poverty, 2020 Searchword: Sweden

<sup>&</sup>lt;sup>16</sup> SoS Annual report on support to persons with disabilities, 2023 Last para p.10.

<sup>&</sup>lt;sup>17</sup> SCB Information about Consumer Price Index and inflation.

<sup>&</sup>lt;sup>18</sup> SCB Information on Salary development 1992 - 2022

12 Many decisions affecting individuals' rights are made at the municipal or regional level. Municipalities apply different fees, local rules and interpretations with inequalities across the country.<sup>19</sup>

13 Lack of national indicators for follow up of disability policy in regions and municipalities, issues include fragmentation and low political priority. <sup>20</sup> Follow up in municipalities is still voluntary<sup>21</sup>.

#### Recommendations articles 1-4

- A. Ensure that definitions in laws, regulations, and statistics correspond to the convention's non-exhaustive determination of who should have access to rights.
- B. Urgently initiate an independent gap analysis of Swedish law and practice so that measures can be taken to incorporate the rights under the convention into Swedish law with effective access to remedies to enforce these rights.
- C. Amend the committee regulations and introduce impact assessments in directives for new legislation and policies based on the convention.
- D. Develop a national action plan with clear targets and indicators to implement the CRPD and systematically address recommendations from the committee in the whole country with funded, effective and meaningful active involvement of OPD:s.
- E. Develop a process for inclusive budget at the national, regional, and local levels based on reducing inequality for the entire population. These processes should include reporting on how commitments and progressive realization of rights under the convention have been considered.
- F. Ensure active involvement in decision-making in accordance with General Comment 7, with proper funding and legality, by

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<sup>&</sup>lt;sup>19</sup> SoS Annual report on support to persons with disabilities, 2023 p.9-15

<sup>&</sup>lt;sup>20</sup> Report commissioned by County Administrative Board on <u>Disability Policy - work</u> in regions and municipalities 2023 Page 34 and 35

<sup>&</sup>lt;sup>21</sup> MFD uppföljning i kommuner 2023 191 out of 290 replies to survey, p.5

- appointing a commission of inquiry and making changes to regulations.
- G. Develop mandatory national indicators to monitor the convention and Agenda 2030 in line with the UN's work to eliminate inequalities in implementation across the country.

# Specific Rights (Arts. 5–30)

# Article 5 Equality and non-discrimination

14 Discrimination complaints related to disability increased and more cases are taken to court since the appointment of a new Equality Ombudsman, DO. There is still a need to strengthen access to justice and equality data<sup>22</sup>.

15 The Constitution<sup>23</sup> chapter 2, clause 12 on discrimination does not include disability.

16 The Discrimination Act does not cover intersectional and multiple discrimination. DO has identified serious harassment and lack of support in schools related to intersection disability and ethnicity<sup>24</sup> but intersections including disability and LGBTQI where there are differences in regulation related to harassment etc has not yet been studied although issues exist<sup>25</sup>.

17 Inadequate accessibility in the Discrimination Act does not cover for example the public sector<sup>26</sup> and housing<sup>27</sup>. It is related to existing specifications "where such measures are reasonable on the basis of accessibility requirements in laws and other statutes".<sup>28</sup>

18 Anti-discrimination bureaus report barriers to access to justice. Very few can get legal representation and take the economic risk that you may have to pay legal cost of you lose a discrimination court case.<sup>29</sup> The

<sup>&</sup>lt;sup>22</sup> DO The State of Discrimination 2023, Page 14-15

<sup>&</sup>lt;sup>23</sup> Instrument of Government, Chapter 2, art 12

<sup>&</sup>lt;sup>24</sup> DO Report on intersectional discrimination Page 14 and 41

<sup>&</sup>lt;sup>25</sup> UN Human Rights Special Procedures <u>Joint statement LGBT Persons with</u> Disabilities 2023

<sup>&</sup>lt;sup>26</sup> DO The State of Discrimination 2023, Page 14-15

<sup>&</sup>lt;sup>27</sup> DO <u>Proposal to remove include housing in relation to inadequate accessibility in the Discrimination Act</u>

<sup>&</sup>lt;sup>28</sup> Discrimination Act 2008:567 Chapter 1, section 4, para 3

<sup>&</sup>lt;sup>29</sup>Antidiscrimination seminar on Access to Justice in the Parliament October 2023

situation gets worse with the increased risk for poverty for persons with disabilities.

19 The Equality Ombudsman quality analysis on discrimination complaints concerning children with disabilities in schools show lack of support and harassments over time<sup>30</sup>. Despite some court cases are won, the remedies are not dissuasive enough. CRC committee recommend easy to access complaint mechanisms<sup>31</sup>. (See also article 24 about lack of support in education.)

20 Active measures to prevent discrimination include inadequate accessibility but interpreted to just be prepared if necessary<sup>32</sup> and not included in general guidance on the obligations<sup>33</sup>.

21 The government did not implement recommendations from the CRPD committee about remedy in the individual complaint from Richard Sahlin<sup>34</sup>.

#### **Recommendations article 5**

- A. Add disability to chapter 2 art 12 in the Instrument of Government.
- B. Adress gaps in the Discrimination Act so that reasonable accommodation and accessibility measures applies to all areas of society, including public sector and housing, to comply with CRPD article 2, 5, 9 and General Comment No. 2 and 6.
- C. Ensure effective protection against discrimination with dissuasive legal remedies for individuals who seek compensation and measures to ensure prevention of discrimination related to all intersections.

<sup>&</sup>lt;sup>30</sup> DO, <u>Report analysing received discrimination complaints from pupils with disabilities</u>, December 2023

<sup>&</sup>lt;sup>31</sup> CRC/C/SWE/CO/6-7 para 12 and 26 b)

<sup>&</sup>lt;sup>32</sup> DO, Q and A about inadequate measures as part of active measures, webpage collected December 2023.

<sup>&</sup>lt;sup>33</sup> DO, <u>Active measures</u>, webpage collected December 2023 <a href="https://aktiva-atgarder.do.se/">https://aktiva-atgarder.do.se/</a>

 $<sup>^{34}</sup>$  Answer from state not published, on Jurisprudence <u>CRPD/C/23/D/45/20</u>18 Sahlin

- D. Review the Discrimination Act's requirements for active measures to eliminate the risk of discrimination to comply with article 5 and prevent discrimination by employers and educational institutions in the form of inadequate accessibility and ensure effective enforcement.
- E. Allocate resources to develop strategies, measures, and legal protections to address multiple and intersectional discrimination, especially concerning LGBTQI, ethnicity, and age.

#### Article 6 Women with disabilities

22 Increased knowledge about violence against girls and women with disabilities does not seem to have effect on outcomes. Public agencies have worked with training material and reports for many years<sup>35</sup>.

23 CEDAW committee made several recommendations 2021 regarding girls and women with disabilities<sup>36</sup>. Lack of systematic approach to disaggregated intersectional data in many areas, such as gender budgeting and policy, including sexual and reproductive health rights and access to justice when subjected to sexual abuse in courts.

24 Review of the implementation of the Istanbul Convention has started with reports from the State<sup>37</sup> and CSO recommendations regarding protection and inclusion of women and girls with disabilities<sup>38</sup>.

25 There is a clear difference in how men and women receive societal support and assistance in the labour market. Women with disabilities are overrepresented in the group whose disposable income falls below 60 percent of the median income, which is the relative poverty threshold<sup>39</sup>.

#### **Recommendations article 6**

A. Ensure intersectional and anti-discriminatory analysis in all measures related gender equality policy and legislation,

<sup>&</sup>lt;sup>35</sup> SoS <u>Information on violence against women with disabilities</u>. and <u>Training material</u> from 2011

<sup>&</sup>lt;sup>36</sup> CEDAW/C/SWE/CO/10 para 10a, 12b, 20, 24a, 24f, 28a, 32e, 34c, 34d, 36b, 42,

<sup>&</sup>lt;sup>37</sup> Government Report Istanbul Convention 2023

<sup>&</sup>lt;sup>38</sup> Swedish Disability Rights Federation <u>Shadowreport Istanbul convention</u> (<u>funktionsratt.se</u>) 2023

<sup>&</sup>lt;sup>39</sup> SOU2022:4 p.92 and section 3.1 p.650

- including disaggregated data on women and girls with disabilities in areas covering for example economy, access to support services, health, education, work and violence.
- B. Increase budgeting and efforts in the national strategy against violence against women with disabilities to include concrete measures and indicators, for example for accessible shelters and access to legal aid, so that outcomes can be monitored.

#### Article 7 Children with disabilities CRD

26 The CRC committee issued several recommendations in 2023 to ensure the rights of children with disabilities in Sweden, including measures to allocate budget for support services and inclusive education, stop violence, coercive measures in institutions and ensure complaint mechanisms and access to justice.<sup>40</sup>

27 Children and young persons with disabilities are overrepresented in compulsory care and are taken into custody under the Youth Care Act<sup>41</sup> and LPT Law. The institutions have been criticized for use of violence in several reports<sup>42</sup> <sup>43</sup> <sup>44</sup> (LPT law). Children and young persons with disabilities are overrepresented in institutions for care (HVB) <sup>45</sup> with reference to The Care of Young Persons (Special Provisions) Act 1990:272. 71 percent of the children and young persons placed HVB) have psychiatric diagnosis. <sup>46</sup> Sexual assaults often committed by staff against girls placed in locked institutions run by the National Board of Institutional Care (SiS) <sup>47</sup> <sup>48</sup>.

28 The legal system lacks competence to handle cases where children with disabilities are both victims and suspected young offenders, leading to a situation of legal uncertainty for children with disabilities<sup>49</sup>.

<sup>46</sup> SoS Report Care of Young persons (HVB) 2019 Page 7

<sup>40</sup> CRC/C/SWE/CO/6-7 Para 31, 9b, 10, 17, 19b, 20, 25, 26, 29, 33, 34, 38c, 41a, 45, 46

<sup>&</sup>lt;sup>41</sup> ISF Barnens bästa SIS-hem 2023 Page 1

<sup>&</sup>lt;sup>42</sup> IVO Monitoring report 2021-2022 SIS-hem for example Section 2.2.7 and 2.7

<sup>&</sup>lt;sup>43</sup> Childrens Rights Bureau ...och jag kunde inte andas 2021

<sup>44</sup> IVO Brister I psykiatrisk tvångsvård av barn, 2023

<sup>&</sup>lt;sup>45</sup> SOU 2023:66 p.203

<sup>&</sup>lt;sup>47</sup> Childrens Rights Bureau ...och jag kund inte andas 2021

<sup>&</sup>lt;sup>48</sup> Childrens Rights Bureau Vem ska tro på mig? 2023 / 2023

 $<sup>^{49}\,\</sup>mathrm{SoS}\,\underline{\mathrm{Risk}}$  och behov för barn och unga som begår brott eller har annat normbrytande beteende 2020 p.13-15

The government started an inquiry about stronger punishment for young offenders without mentioning disability<sup>50</sup>.

- 29 Civil Society have given comprehensive information about the severe situation for rights of children with disabilities<sup>51</sup>. Public agencies that report about the situation of children with disabilities have emphasized the higher risk for violence, bullying, and sexual abuse<sup>52</sup>.
- 30 Recent proposals from government inquiries have suggested several amendments to strategies to prevent violence against children<sup>53</sup> and to strengthen the rights by funding of children's rights bureaus.<sup>54</sup>
- 31 Mental health issues among children and young persons, and suicide still increasing. In ages 15-24 a yearly increase of suicides with one percent for the last 20 years<sup>55</sup>.

#### **Recommendations article 7**

- A. Ensure effective measures with adequate funding focusing on preventing violence against children with disabilities in the upcoming national strategy.
- B. Allocate funding for research on effective measures to increase mental health among children and young persons with disabilities.
- C. Implement comprehensive protection for children and young persons with disabilities who are deprived of their liberty due to the consequences of their disabilities, with access to justice.
- D. Implement measures and follow-up to ensure that children, parents, staff, the public, and especially the legal system and decision-makers receive equitable and adequate education and information about children with disabilities and the consequences of disabilities.

<sup>51</sup> Report-from-Civil-Society-Organisations-working-with-Child-Rights-2023.pdf (barnkonventionen.se) Search word disability

<sup>&</sup>lt;sup>50</sup>Dir 2023:112

<sup>&</sup>lt;sup>52</sup> SoS Information about violence against children with disabilities.

<sup>&</sup>lt;sup>53</sup> SOU2022:70

<sup>&</sup>lt;sup>54</sup> SOU2023:40 p 89

<sup>55</sup> Stockholm Region Web post

E. Establish funding for age appropriate disability inclusive independent complaint mechanisms, legal representation for access to justice and compensation. See also article 13.

### **Article 8 Awareness-raising**

32 The ordinance 2001:526<sup>56</sup> on public agencies responsibility to implement the Disability Policy was revised in 2014 to include mentioning of the CRPD.

33 The yearly voluntary follow up survey to public agencies is based on self-assessment with few mainstreamed awareness raising activities. The percentage of answers decreased in 2022 to 85 percent public agencies, 81 percent regions and 66 percent for municipalities<sup>57</sup>. 22 percent answer there is some knowledge about the CRPD in their agency (decrease from 27 percent in 2021)<sup>58</sup>.

34 No initiative to follow up awareness in society or whether relevant professional training includes knowledge about the CRPD.

35 Disability policy has not changed focus to Disability Rights, the Disability ombudsman closed down 2008, and was replaced by a public agency supporting the government policy, and there is no dedicated yearly budget allocated for realizing CRPD.<sup>59</sup>

36 There are no measurable outcomes of the limited initiative 2015 – 2017<sup>60</sup> to raise awareness about human rights after the UN's recommendation in 2014. Proposals from civil society on measures have not been prioritised.<sup>61</sup>

37 The CRPD is not known, and seldom used for analysis in public inquiries, reports, referrals, positions from Public Agencies, Parliament, regions, municipalities, the legal system, the public, or the private sector. Promising civil society initiative in the region of Stockholm,

<sup>&</sup>lt;sup>56</sup> SFS Ordinance 2001:526

<sup>&</sup>lt;sup>57</sup> MFD Yearly report 2022 p 42

<sup>&</sup>lt;sup>58</sup> MFD follow up in public agencies 2022-2023 p 7-10.

<sup>&</sup>lt;sup>59</sup> State Budget 2024 Disability Policy 4.6 and 7.6 Child rights policy – The policy changed name in 2008, with an Ombudsman for children and a yearly budget allocated to "realise the CRC" since 2005.

<sup>&</sup>lt;sup>60</sup> MFD Kommunikationssatsning om rättigheter för personer med funktionsnedsättning 2018

 $<sup>^{61}</sup>$  CSO submission LoIPR 2018 p 6, art 8

introducing a tool for impact assessments in decision-making<sup>62</sup>, but very few OPD have adequate funding and capacity.

38 There is no systematic monitoring of the portrayal of persons with disabilities in the media. An analysis from 2007<sup>63</sup> showed that the media often frames persons with disabilities based on a few diseases and diagnoses, with a predominantly negative perspective, reinforcing the image of hopelessness, ill-health, problems, or exclusion. A smaller study<sup>64</sup> in 2018 confirmed issues with only about 1.2 percent visibility of persons with disabilities in all news items from public service media.

#### **Recommendations article 8**

- A. Allocate adequate resources on yearly basis to raise awareness on the CRPD and the human rights approach at various levels of society in the long term, including mapping of curricula for relevant professional courses and training.
- B. Establish, in close dialogue with the disability rights movement, fully financed in-depth targeted training programs for decision makers and high-level policy officers the obligations related to implementation of the CRPD.
- C. Initiate media research on representation of persons with disabilities, and encourage media accountability through guidelines, independent monitoring on inclusion of persons with disabilities in public media.

# Article 9 Accessibility

39 The Parliament decision in 2017 to focus Disability policy on the principle of universal design, the removal of existing barriers for accessibility, individual support for independence, and to prevent and counter discrimination is not linked to concrete targets, budget or measurable outcomes.

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<sup>62</sup> Funktionsrätt Stockholms län FKB

<sup>63</sup> Ghersetti Bilden av funktionshinder 2007

<sup>&</sup>lt;sup>64</sup> PSfunk Valet 2018

40 The government reply to UPR recommendations<sup>65</sup> states that "accessibility can be accomplished without increased funding" with reference to the "principle of responsibility and financing", described in the government bill for disability policy: "every sector in society is responsible for implementing disability policy. It is the responsibility of the entire society to ensure that persons are not excluded, and that the competence of all individuals is utilized."<sup>66</sup>

41 Universal design is not mainstreamed in research (art 4.1 f) and new technology such as AI, with increasing risk for exclusion and creating new barriers especially for persons with cognitive disabilities.

42 Full transposition of EU regulations on digital and media accessibility have been delayed partly linked to challenges to combine accessibility requirements with the government interpretation of the constitutional Freedom of Expression Act<sup>6768</sup>.

43 EU open infringement procedure related to the transposition of the European Accessibility Act in Swedish Law<sup>69</sup>. The Swedish Disability Rights Federation has presented a correlation table<sup>70</sup> about change of title limiting the scope, lack of implementing requirements in law, for example articles 24 and 29 in the directive.

44 Yearly survey of concrete outcomes of accessibility improvements in public agencies linked to the ordinance 2001:526 ceased in 2016<sup>71</sup>. The current survey asks for plans, not outcomes. The update of the concrete guidelines for removing barriers for accessibility related to the ordinance stopped in 2015 and later deleted which led to unanswered critique<sup>72</sup>. The replacement web tool Focus participation<sup>73</sup> is based on questions not guidelines.

45 A survey 2021 about compulsory accessibility requirements in Public Procurement Act show that 55 percent do not make the requirements, and when they are made it is in very few cases<sup>74</sup>.

<sup>67</sup> Prop2022/23:42 chap 5.2

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<sup>65</sup> UPR Recommendations 156.278 and 156.279 were noted with comments

<sup>66</sup> Prop 2016/17:188 p 78

<sup>&</sup>lt;sup>68</sup> The Swedish constitution in English

<sup>&</sup>lt;sup>69</sup> European Commission <u>Infringement decision</u> Collected 2023-10-31

<sup>&</sup>lt;sup>70</sup> Swedish Disability Rights Federation Draft correlation table 2023

<sup>&</sup>lt;sup>71</sup> MFD Så tillgänglig är staten 2016

<sup>&</sup>lt;sup>72</sup> Swedish Disability Rights Federation Skrivelse Riv hindren 2019

<sup>&</sup>lt;sup>73</sup> MFD Verktyg för tillgänglighetsarbete This version collected 2023-10-31

<sup>&</sup>lt;sup>74</sup> MFD <u>Follow up of Disability Policy 2021</u> p 54

46 OPD input<sup>75</sup> to the European Court of Auditors, ECA, on lack of national implementation and monitoring of CRPD and accessibility in EU funding despite compulsory requirements. ECA recommends i.e. legislation equal treatment and active implementation of European Accessibility Act.<sup>76</sup>

47 The Swedish National Board of Housing, Building and Planning proposed revised functional building requirements<sup>77</sup> in 2023 by removing standards and detailed guidelines. The proposed amendments received critique<sup>78</sup> from OPD:s and industry. The government has asked the agency to propose reduced accessibility requirements for student housing<sup>79</sup>.

48 PWD and OPD:s have limited possibilities to make complaints on failure to include accessibility requirements<sup>80</sup>, and fragmented responsibility, the absence of using sanctions and resources for monitoring creates new barriers in society.

49 Public agencies for built environment and consumers etc left European accessibility standardisation, despite recommendations to participate<sup>81</sup>.

#### **Recommendations article 9**

- A. Establish a national action plan with adequate funding, specific targets, timeline to systematically remove existing accessibility barriers throughout the country.
- B. Establish a national Access board to coordinate standards, guidelines, complaints and monitoring of accessibility and universal design in different sectors including representatives from OPD:s.
- C. Ensure that accessibility following a universal design approach is included in all new developments, including in digitalization

<sup>75</sup> Submission European Court of Auditors, ECA CRPD June 2022

<sup>&</sup>lt;sup>76</sup> ECA SR2023:20

<sup>&</sup>lt;sup>77</sup> BoV <u>Möjligheternas Byggregler</u>

<sup>&</sup>lt;sup>78</sup> Answers to the Swedish National Board of Housing, Building and Planning referral concerning accessibility

<sup>&</sup>lt;sup>79</sup> BoV <u>Housing for students</u> /

<sup>80</sup> MFD Referral 2021/0379-1

<sup>81</sup> The National Board of Trade Standards green transition Page 23 section 4.4.3

- policy, innovations, and research funded with public funds in accordance with Article 4 and General Comment 2.
- D. Review regulation and standards for accessibility in the built environment, transportation, public information, and communication, including e-identification and emergency.
- E. Establish a monitoring system to ensure enforcement of mandatory accessibility requirements and universal design in public procurement.
- F. Ensure government agencies participate in standardisation and provide funding for disability organizations to participate.

#### Article 10 Right to life

See the report submitted by Civil Rights Defenders for the 30<sup>th</sup> session of the CRPD committee.

### Article 11 Situations of risk and humanitarian emergencies

50 There is a lack of inclusive crisis preparedness. There is no systematic method for including, ensuring, and following up on disability rights in situations of risk and emergencies in policy.

51 There are examples where the safety of persons with disabilities could not be ensured during various crises. During the COVID-19 pandemic, it took several weeks before accessible<sup>82</sup> information<sup>83</sup> about the coronavirus was made available on the responsible authorities' websites. Many persons with disabilities<sup>84</sup> experienced cancelled<sup>85</sup> healthcare interventions, daily activities, and other support, for example, in schools. Many reported poorer mental health because of limitations in their living situation, isolation, worsened finances, increased anxiety, and depression.<sup>8687</sup>

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<sup>82</sup>Prop2022/23:42

<sup>83</sup> Lind Corona Virus

<sup>84</sup> Swedish Disability Rights Federation Web post

<sup>&</sup>lt;sup>85</sup> SoS Annual report support services 2023

<sup>&</sup>lt;sup>86</sup> MFD Pandemic and welfare services

<sup>87</sup> Lyngbäck et al Impact Covid-19 disabled citizens

52 More significantly, the fatality rate upon contracting COVID-19, during a period, was over twice as high<sup>88</sup> among individuals living in residences with special services for adults compared to the general population. No measures were taken to completely protect persons with disabilities from the infection. SKR (Swedish Association of Local Authorities and Regions)<sup>89</sup> made a request for the introduction of a law, albeit temporary, granting municipalities the ability to make their own priorities during the COVID-19 epidemic, something that threatened legal certainty. Very concerning is a recent investigation<sup>90</sup> regarding future infection control, proposing the possibility of forcibly relocating individuals in LSS residences during a new pandemic, something that also contradicts legal security.

53 Despite the Swedish Corona Commission<sup>91</sup> later highlighting that the absence of a plan to protect risk groups was a problem that should have prompted earlier interventions, nothing has been done to create a more inclusive crisis plan.

54 Support material for communicators was developed during the pandemic but was not implemented despite floods and an increased threat level regarding the risk of terror to level 4 ('high') on a 5-degree scale<sup>92</sup> in August 2023.

55 Municipalities do not amend their preparedness plans to include persons with disabilities. Fifty percent of municipalities lack evacuation plans<sup>93</sup> for residences for persons with disabilities. The Swedish Civil Contingencies Agency (MSB) has no information on accessibility in emergency spaces<sup>94</sup>.

#### **Recommendations article 11**

A. Establish procedures for accessible information and communication, accessible preparedness, an accessible emergency number without pre-registration requirements, accessible measures and action plans for information and

<sup>88</sup> SoS Covid-19 LSS

<sup>89</sup> Swedish Disability Rights Federation Web post municipalities

<sup>&</sup>lt;sup>90</sup> SOU2023:56

<sup>91</sup> SO<u>U2022:10</u>

<sup>92</sup> Government Threat level

<sup>93</sup> SoS Evakueringsplaner

<sup>94</sup> SVT Skyddsrum

communication, as well as measures and preparedness to provide persons with disabilities the support they need during crises, disasters, and humanitarian emergencies.

B. Involve organizations representing persons with disabilities in the development of crisis preparedness.

# Article 12 Equal recognition before the law

56 The government has not taken steps to move from substituted to supported decision-making. Limited proposals from government inquiry on guardianship presented in 2021<sup>95</sup> have not been implemented. The government inquiry did not make an analysis of the paradigm shift and concerns substituted decision-making.

57 Swedish preparatory works suggest that the legislation in place is crucial in the protection of persons who lack the ability to take care of their financial and personal affairs themselves. 96 The Supreme Court has underlined that physical disability that does not affect the cognitive ability or the ability to take decisions, does not create grounds for trusteeship<sup>97</sup>.

58 Over the last eight years there has been an increase in the number of persons in trusteeship under the Parental Code (1949:381).98 The Council of Legislation has expressed concerns regarding the risk that restrictive decisions could be made on grounds too weak.99

59 Persons with disabilities are not provided with the support and legal aid they need to exercise their legal capacity (see also article 13). In rare cases where legal representation exists there are examples of fraud and persons wrongfully placed under trusteeship. 100

60 There is lack of national coordination, unequal access, and different interpretations in municipalities to the support called "Personligt

<sup>95</sup> SOU2021:36

<sup>&</sup>lt;sup>96</sup> Prop.1987/88:124 p.132.

<sup>&</sup>lt;sup>97</sup> NJA 2018 p. 350

<sup>98</sup> County Administrative Boards, Överförmyndarstatistik, Förvaltarskap enligt föräldrabalken 11 kap. 7 §.

<sup>&</sup>lt;sup>99</sup> Prop. 1987/88:124 p 230.

<sup>&</sup>lt;sup>100</sup> Stockholm District Court, Case No. T 5920-21, 2022-04-21.

Ombud", PO<sup>101</sup>, inspired by case manager systems in UK<sup>102</sup>, to support persons with disabilities, primarily with mental health conditions.<sup>103</sup> 61 Existing electronic identification solutions excludes persons with disabilities with legal guardian and is not in line with the CRPD<sup>104</sup>.

#### Recommendations article 12

- A. Take immediate measures to replace substitute decision-making with supported decision-making, fully compliant with the convention and General Comment 1 and ensure equal access to support in the whole country.
- B. Establish national monitoring system of legal guardians, until a new law for supported decision-making is proposed and implemented.

# **Article 13 Access to justice**

This text complements the report submitted by Civil Rights Defenders for the 30<sup>th</sup> session of the CRPD committee.

62 The complexity of procedures to apply for support, make complaints and understand decisions makes it almost impossible to obtain redress and claim rights in administrative agencies and courts without legal aid<sup>105</sup>.

63 The lack of knowledge and competence in the judiciary, some district courts, and The Swedish National Council for Crime Prevention admit that there is no awareness of CRPD<sup>106</sup>. Children with disabilities are not considered credible in courts.<sup>107</sup>

<sup>101</sup> SoS 2023-9-8764

<sup>&</sup>lt;sup>102</sup> PO <u>profession is born</u> Page 7

<sup>&</sup>lt;sup>103</sup> Ordinance <u>SFS2013:522</u>

<sup>&</sup>lt;sup>104</sup> SOU2023:61 Page 103 and 108

<sup>&</sup>lt;sup>105</sup> Al Hasseini et al, Lund University, From Commitment to Reality, 2023 Chapter 4

<sup>&</sup>lt;sup>106</sup> Brå report 2016:8 "Målsägandes medverkan i rättsprocessen", 2016. p. 80-81.

<sup>&</sup>lt;sup>107</sup> Al Hasseini et al, Lund University, From Commitment to Reality, 2023 Page 31 -33

64 The state through the Chancellor of Justice puts the responsibility for procedural accommodations on the public defender, in a case concerning a man with autism spectrum disorder<sup>108</sup>

65 A study about the situation in administrative courts in Sweden, encompassing (among others) cases concerning the Swedish Act on Support and Service for Persons with Certain Functional Impairments (LSS), reveals that unrepresented parties have a 92 percent loss rate, while the figure drops to 74 percent loss rate in cases where the individual is assisted by a lawyer.<sup>109</sup>

66 Economic barriers for access to justice include lack of affordable expertise especially in the administrative courts and "loser pays" rule related to discrimination<sup>110</sup>. No initiative has been made to act on proposals based on research<sup>111</sup> about inequality to amend the legal aid act and ensure need of legal support<sup>112</sup>.

67 Lower incomes and reduced financing for organisations of persons with disabilities and human right advocacy groups<sup>113</sup>, makes it even more difficult to access justice. Most local support centres that once were started with state project financing, do not exist for lack of sustainable financing from municipalities or regions<sup>114</sup>.

#### Recommendations article 13

A. Ensure and monitor effective continuous training of staff in the justice system to increase the knowledge about the rights of persons with disabilities, including knowledge about violence against persons with disabilities, accessibility requirements.

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 $<sup>^{108}</sup>$  Chancellor of Justice, dnr. 6984-19-4.3.2, Skadeståndsanspråk mot staten med hänvisning till polis och åklagares agerande under en förundersökning och domstolsprocess.

<sup>&</sup>lt;sup>109</sup> Lorentzon et al <u>Ombudsfördel i förvaltningsmål – ett empiriskt bidrag till teorin</u> om 'lawyer advantage'"2022

<sup>&</sup>lt;sup>110</sup> European Commission <u>Country report non-discrimination Sweden</u> 2021, Page 9 section 5

<sup>&</sup>lt;sup>111</sup>S.Wejedal, Thesis <u>Rätten till biträde</u>, 2017 abstract

 $<sup>^{112}</sup>$  The Swedish Agency for Participation, <u>Mäns våld mot kvinnor med funktionsnedsättning (mfd.se)</u>, Page 52 and 54

<sup>&</sup>lt;sup>113</sup>The Swedish Disability Rights Federation, <u>Disability Rights Bureau project report</u> 2022

<sup>&</sup>lt;sup>114</sup>J Bolling, The Swedish Inheritance Fund, Evaluation report Brukarstödscentra, 2007

- B. Review the Swedish law to ensure procedural and ageappropriate accommodations in criminal, civil and administrative proceedings.
- C. Conduct a comprehensive review of the legal aid act and remove economical barriers to ensure access to justice especially in administrative courts and court cases related to discrimination.
- D. Establish and fund independent judicial support mechanisms for the rights of adults with disabilities, inspired by the measures proposed for children (see article 7).

## Article 14 Liberty and security of the person

See the report submitted by Civil Rights Defenders for the 30<sup>th</sup> session of the CRPD committee.

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

See the report submitted by Civil Rights Defenders for the 30<sup>th</sup> session of the CRPD committee.

#### Article 16 Freedom from exploitation, violence and abuse

The text complements the report submitted by Civil Rights Defenders for the 30<sup>th</sup> session of the CRPD committee. See also articles 6 and 7 about violence against women and children.

68 Persons with disabilities being exposed to physical, psychological and sexual violence in both childhood and adulthood continues. More than twice as many men with disabilities as men without disabilities report having experienced sexual violence in adulthood. Overall, the increase in risk is more significant for women with disabilities compared to men with disabilities. <sup>115</sup>

69 Any form of disability almost doubled the likelihood of having been exposed to psychological abuse, physical abuse, sexual abuse and bullying for children and young persons. In addition, the risk of sexual

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<sup>&</sup>lt;sup>115</sup> The Swedish Agency for Participation, <u>Våld mot personer med</u> <u>funktionsnedsättning</u>, 2023 Page 31-32

exploitation doubled. 116 Children with neuropsychiatric disabilities are nearly twice as likely to be the victims of frequent harassment and bullying in schools. 117

70 Despite questions from the CRPD committee Swedish legislation on hate crime does not include disability as a specific ground. 118 119 Recently a government inquiry proposed protection related to gender, but no initiative to ensure protection related to disability. 120 The Criminal Code and the Freedom of the Press Act do not protect individuals with disabilities from threats and contempt in the same way as other groups. Disability is not part of national statistics on hate crimes, nor is it included in policy initiatives to reduce hate crimes, for example, online.

#### **Recommendations article 16**

A Amend the Swedish legislation related to hate crimes and insults to include protection for persons with disabilities on equal basis with other groups.

### Article 17 Protection of personal integrity

71 Persons with disabilities are still subject to medical treatments, coercive and restrictive measures in psychiatric care<sup>121</sup>, but also in group homes<sup>122</sup> and special housing without their free and informed consent, particularly persons still under guardianship.

72 This also occurs in violation of the Health and Medical Services Act<sup>123</sup> and in accordance with the supplementary Compulsory Care Legislation<sup>124</sup>.

<sup>&</sup>lt;sup>116</sup> Stiftelsen Allmänna Barnhuset and Myndigheten för delaktighet, <u>Mer utsatta än</u> andra (2023), p. 32 para 2

<sup>&</sup>lt;sup>117</sup> Friends, Annual report (2023), p. 8.

<sup>&</sup>lt;sup>118</sup> Al Hasseini et al, Lund University, From Commitment to Reality, 2023 section 3.1.2

<sup>&</sup>lt;sup>119</sup> Independent Living Institute, <u>Implementation of ICERD</u>, <u>Hate crimes migrants</u> with disabilities, 2023

<sup>&</sup>lt;sup>120</sup>, <u>SOU 2023:80</u>, p. 32, chap 5.2, p. 55 no proposal to add disability to Swedish Criminal Code Chap 29, §2.7

<sup>121</sup> IVO referral SOU2023:5

<sup>&</sup>lt;sup>122</sup> IVO <u>2023:14</u> p. 7

<sup>123</sup> SFS2017:30 para 4

<sup>124</sup> SFS1991:1128

#### **Recommendations article 17**

A Take legislative and other measures necessary to prevent and stop non-consensual medical treatments, coercive and restrictive measures.

# Article 18 Liberty of movement and citizenship

73 The current government's reform agenda in the so called Tidö-agreement<sup>125,126</sup> on migration legislation lacks a human rights perspective<sup>127</sup> and disadvantages migrants with disabilities<sup>128</sup>. There is already a hierarchy between different migration statuses<sup>129</sup> that affect social rights.

74 All forms of welfare such as full access to healthcare<sup>130</sup>, rights in The Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS), such as personal assistance and special housing are conditioned with either permanent residence or citizenship.

75 There are already several legislative proposals that disadvantage migrants with disabilities in various ways. <sup>131</sup> Permanent residence status is proposed to be removed and the possibility to apply for citizenship is proposed to be limited with new conditions <sup>132</sup>, such as the requirement for full ability to support oneself for at least 8 years, conditions that disadvantage migrants with disabilities. Persons that live in Sweden with permanent residence but without citizenship are at risk to be expelled.

76 The right to free movement within Sweden is not guaranteed, as the municipal self-government means that a person can lose their support services when moving to another municipality.

#### **Recommendations article 18**

A. Monitor that all disabled persons regardless of their migration status can get access to individualised disability support as a

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<sup>125</sup> Liberalerna Tidö-avtalet

<sup>&</sup>lt;sup>126</sup> Arena idé <u>Integrationens slut</u>

<sup>&</sup>lt;sup>127</sup> ILI ICERD Migrants with disabilities

<sup>&</sup>lt;sup>128</sup> MFD Stödja migranter med funktionsnedsättning

<sup>&</sup>lt;sup>129</sup> MFD <u>Kartor mottagningssystemet</u>

<sup>&</sup>lt;sup>130</sup> Migrationsverket <u>Medan du väntar</u>

<sup>&</sup>lt;sup>131</sup> ILI Migrants with disabilities

<sup>132</sup> Dir2023:129

- precondition for their equal enjoyment of economic, social and cultural rights without discrimination.
- B. Develop a national regulatory framework for assessing rights for persons with disabilities with the aim of guaranteeing equality across the country and enabling free movement.

# Article 19 Living independently and being included in the community

77 Sweden does not fulfil the state party obligation to ensure freedom to live in the community and access to individual support services with choices equal to others.

78 Since the introduction of LSS<sup>133</sup> in 1994, the legal application has gradually eroded the different rights granted by the law, among them, respect for self-determination, personal assistance, with the consequences that the ability to control one's own life has been restricted for many.

79 A legislative change on January 1, 2023<sup>134</sup>, regarding strengthened rights to personal assistance was expected to provide increased opportunities for personal assistance for children and individuals with mental disabilities. Additionally, individuals who lost their personal assistance between 2015 and 2022<sup>135</sup> <sup>136</sup> were expected to be granted assistance again. The follow-up in November 2023 shows that the right to assistance has, on the contrary, been weakened<sup>137</sup>.

80 The right to personal assistance is limited for persons over 66.<sup>138</sup> Persons with disabilities that do not get support via LSS, can get support from SOL but only for "reasonable standard of living" <sup>139</sup> compared to the right to good living conditions <sup>140</sup> in LSS.

<sup>133</sup> SFS1993:387

<sup>&</sup>lt;sup>134</sup>SoS ComNr9/2022

<sup>&</sup>lt;sup>135</sup> HejaOlika article December 2023

<sup>&</sup>lt;sup>136</sup> FK Statistics personal assistance

<sup>137</sup> HejaOlika Article problems 2023

<sup>138</sup> SFS1993:387 § 9 b

<sup>139</sup> SFS2001:453 4Chap §1para4

<sup>140</sup> SFS1993:387 §7

81 The right to support by LSS and SOL also varies between municipalities, which, in practice, prevents persons from changing their place of residence without risking losing their support.<sup>141</sup>

82 The state does not take responsibility for municipal LSS interventions, neither in terms of needs assessments nor the implementation of approved interventions.

83 OPDs observe violations of the right to active participation in society<sup>142</sup>. For example, there are significant reductions in the right to accompaniment<sup>143</sup>, one of the rights in LSS, which also hinder self-determination and full participation in society.

84 The lack<sup>144</sup> of access to individual support services and safe, accessible, and community-based housing on an equal basis with others within the same community also restricts the right to choose how, where and with whom to live.

85 Among children with extensive needs, the National Board of Health and Welfare warns<sup>145</sup> that more children are at risk of moving away from their families due to inadequate support.

86 The recent report<sup>146</sup> by the Inspection for Health and Care highlights concerning developments where restraint measures are regularly used in residences for persons with disabilities. The number of residents is increasing and co-location with daily activities and nursing homes is occurring, leading to institutionalization.

#### Recommendations article 19

A. Clarify in all legislation related to support services and forms of service for persons with disabilities, including LSS, how the design and scope of services contribute to fulfil Article 19, in line with General Comment Number 5, GC5.

<sup>143</sup> SoS2023-6-8641

<sup>141</sup> SoS 2023-4-8476 p.9 and 49

<sup>&</sup>lt;sup>142</sup> CRPD GC5

<sup>&</sup>lt;sup>144</sup> ILI Deinstitionalisation

<sup>&</sup>lt;sup>145</sup> SoS 2017-12-19

<sup>&</sup>lt;sup>146</sup> SoS <u>Annual report support services 2023</u> Segnestam Larsson et al <u>Kommunala riktlinjer</u>

- B. Ensure the right to personal assistance in legislation and that its design, scope, and level of cash transfers in line with GC5.
- C. Conduct regular yearly national monitoring on support, for persons with disabilities, including LSS to ensure that the quality of services throughout the country complies with Article 19 as per GC5.
- D. Adopt an action plan including timeline and funding to ensure access to safe, accessible, and community-based housing in line with GC5 to prevent reinstitutionalization.

#### **Article 20 Personal mobility**

87 Despite legislation from 1979 on accessible public transport, there are still inaccessible vehicles and bus stops according to the government's indicator for progress. <sup>147</sup> The Government Agency Transport Analysis updated follow-up report highlights a positive trend <sup>148</sup>, in contrast to protests from organisations of persons with disabilities <sup>149</sup> regarding lack of information and assistance when travelling, apart from physical barriers.

88 Personal mobility is reduced for persons in need of accompanying person service including persons living in "special accommodation for older persons", group homes and especially blind persons.<sup>150</sup>

89 Regions, responsible for public procurement of transport, claim using compulsory accessibility requirements to a high extent<sup>151</sup>. Since privatisation of train transport, mix of companies with old train sets and modern trains.

90 Fewer persons are granted "special transport services". Proposed legal amendments<sup>152</sup> of the negative effects of court rulings have not been implemented.

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<sup>147</sup> State budget 2024 Page 111

<sup>&</sup>lt;sup>148</sup> Transport Analysis Kollektivtrafikens tillgänglighet 2023

<sup>&</sup>lt;sup>149</sup> Funktionsrätt Stockholms län <u>Tillgängliga resor</u>

<sup>&</sup>lt;sup>150</sup> SoS Press communication

<sup>&</sup>lt;sup>151</sup> Public Procurement Agency report p.126

https://www.upphandlingsmyndigheten.se/globalassets/dokument/publikationer/nationella-upphandlingsrapporten-2023.pdf

<sup>&</sup>lt;sup>152</sup> Transport Analysis Clearer criteria for special transport 2023

91 Users of accommodated cars report local differences and increased costs for parking, discrimination for lack of accessible fuel stations<sup>153</sup> and charging<sup>154</sup>.

#### **Recommendations article 20**

- A. Develop a national plan with revised indicators to ensure the right to personal mobility with active involvement of OPD:s all over the country. This includes assistance, assistive devices, access to adapted vehicles, procurement of special transportation including school transport, and personal transport at a reasonable cost.
- B. Update legislation to ensure the right to personal mobility across the country with easy to access to complaint mechanisms and compensation.

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

92 To enable accessibility requirements for media content distributed digitally, reviews of the constitution are considered necessary. Issues have also been raised in the bill on transposition of the European Accessibility Act, where the Swedish law<sup>155</sup> has restricted the definition of e-books in article 2, different from the directive article 3 definition 41<sup>156</sup>.

93 The right to alternative and enhanced communication is not clearly expressed in any law.

94 Hateful expressions towards persons with disabilities are excluded from national legislation 157.

<sup>156</sup> EU Directive 2019/882

<sup>&</sup>lt;sup>153</sup> Funktionshinderpolitik News article 2022

<sup>&</sup>lt;sup>154</sup> Byggtjänst Article laddstationer 2021

<sup>155</sup> SFS2023:524

<sup>&</sup>lt;sup>157</sup> Swedish Police Authority Fakta hatbrott

#### **Recommendations article 21**

- A. Eliminate barriers in all legislation, including the constitution, to enable requirements for digital accessibility, alternative and enhanced communication, and universal design to ensure access to information.
- B. Monitor prevalence of online hate speech and derogatory expressions related to individuals with disabilities in the media.

# Article 22 Respect for privacy

95 Measures about sharing sensitive data between government agencies refers to for example CRC but not to CRPD<sup>158</sup>.

96 Issues concerning data protection related to assistive technology and cloud services have been raised<sup>159</sup>.

97 There are concerns that the risk for further violating respect for privacy when assessing the need for personal assistance<sup>160</sup> with increased estimates of criminal gangs and fraud in the welfare system. 161

98 The Swedish Social Insurance Agency and municipalities often conduct<sup>162</sup> privacy-invasive assessments to evaluate the need for support and various services, such as personal assistance and companionship, including monitoring the time it takes to go to the toilet or to shower.

#### **Recommendations article 22**

- A. Develop criteria for decision-making and monitoring to ensure that individuals with disabilities can influence who should have access to data that may pose a risk to their privacy.
- B. State guidelines must be developed for needs assessments of services, including personal assistance, to ensure that they are

<sup>&</sup>lt;sup>158</sup> Dir2023:146

<sup>&</sup>lt;sup>159</sup> DPforum Personlig Integritet 2022

<sup>&</sup>lt;sup>160</sup> HejaOlika <u>Läget personlig assistans</u> 2023

<sup>&</sup>lt;sup>161</sup> TV4 Välfärdssystem mjölkas

<sup>&</sup>lt;sup>162</sup> HejaOlika <u>Personliga rättigheter</u>

conducted in a manner that respects privacy and is proportionate.

#### Article 23 Respect for home and the family

99 Support for equal opportunities in families with children or adults with disabilities shows significant shortcomings<sup>163</sup> <sup>164</sup>; lack of access to all forms of support and widespread ignorance at all levels, including healthcare, municipal support, and services, as well as in childcare and schools. These shortcomings were pointed out already back in 2011. The report<sup>165</sup> led to some measures, but overall, the situation remains largely unchanged, and often even worse.

100 A more restrictive migration policy is now being implemented in Sweden. The reform agenda<sup>166</sup> includes stricter requirements for the possibility of family reunification for migrants<sup>167</sup>, which, among other things, places very high demands on financial capability and the size of housing. This largely affects migrants with disabilities.<sup>168</sup>

#### **Recommendations article 23**

- A. Persons with disabilities should be legally guaranteed equal rights in family life, which includes adequate support from societal authorities for equal parenthood. This support should cover equal assistance to families with children with disabilities, and its effects on equal economic opportunities, health, and life opportunities, especially for women, should be monitored.
- B. The state should ensure that children with disabilities are not separated from their parents against their will.

<sup>165</sup> National Audit Office Samordning 2011

<sup>&</sup>lt;sup>163</sup> Swedish Disability Rights Federation Föräldrar på olika villkor 2022

<sup>&</sup>lt;sup>164</sup> MFD Föräldraskap 2017

<sup>&</sup>lt;sup>166</sup> Government Web Migration prioriteringar Collected Dec2023

<sup>&</sup>lt;sup>167</sup> Prop2023/24:18

<sup>168</sup> ILI ICERD Migrants with disabilities 2023

#### **Article 24 Education**

101 The Swedish school system is not inclusive, and we see a development towards an increasingly segregated school, where fewer students with disabilities receive reasonable accommodations or special support <sup>169,170,171</sup>. An example is changes in the Education Act concerning so-called resource schools <sup>172</sup> and the introduction of emergency schools, where students considered to disrupt the teaching can be placed. More students are placed in Compulsory School for Pupils with Intellectual Disabilities, <sup>173</sup>the number continues to grow <sup>174</sup>, and more than 50 percent are born outside Sweden.

102 The Swedish system of free school choice still makes it possible to reject a student due to organizational and economic challenges<sup>175</sup>,

103 Each year, approximately 15 percent of students graduate from primary school without complete grades<sup>176</sup>, and many of these students have disabilities.

104 An increasing number of students are reporting schools to the Equality Ombudsman<sup>177</sup> for discrimination in the form of inadequate accessibility. In some cases, the lack of reasonable accommodations and special support is not only considered <sup>178</sup> a violation of the Education Act but also of anti-discrimination legislation.

105 One significant barrier for many students with disabilities is that, currently, there is a requirement for special reasons<sup>179</sup> to access personal assistance in school and preschool.

106 The adapted school system exhibits significant shortcomings, especially regarding the percentage of qualified teachers and the

<sup>&</sup>lt;sup>169</sup> Giota, School achievements...over 50 years 2022 News item

<sup>&</sup>lt;sup>170</sup> Swedish Shools Inspectorate Annual report 2022

<sup>171</sup> SPSM Annual report 2022

<sup>&</sup>lt;sup>172</sup> National Agency for Education <u>Aktuella regeländringar</u>

<sup>&</sup>lt;sup>173</sup> DN Fler elever i grundsärskola 2023

<sup>&</sup>lt;sup>174</sup> National Agency for Education Skoltermer

<sup>&</sup>lt;sup>175</sup> Persson et al. Lund University Fritt skolval för vem? 2020

<sup>&</sup>lt;sup>176</sup>National Agency for Education Statistics 2022/23

<sup>&</sup>lt;sup>177</sup>DO, <u>Report analysing received discrimination complaints from pupils with disabilities</u>, December 2023

<sup>&</sup>lt;sup>178</sup> Malmö mot diskriminering Press release 2023

<sup>&</sup>lt;sup>179</sup> FK Assistansersättning för barn

opportunity to progress to upper secondary school, vocational colleges, or adult education.

107 There are deficiencies in support for students even at the upper secondary school and higher education levels<sup>180</sup>, where there is a considerable variation across the country.

108 The government grant to adult education college is not adjusted for ongoing inflation, resulting in layoffs of around 3000 teachers<sup>181</sup> and significant cuts to programs aimed at students with disabilities, including programs that provide basic eligibility for further studies. Even the grants to study associations<sup>182</sup> are significantly reduced, meaning that important activities for persons with disabilities are being cancelled.

109 Currently, it is not possible to monitor the effects of the support interventions children and students with disabilities may receive, if any. 183 A recent investigation 184 proposes clearer and sharper responsibilities to ensure that the conditions for children and students with disabilities in all school forms are continuously monitored.

#### **Recommendations article 24**

- E. Develop an action plan to ensure inclusive and nondiscriminatory education within the school system for all children and students with disabilities in line with General Comment 4.
- F. Monitor the school's implementation of its compensatory responsibility. The requirements must be adhered to, and clear consequences should be imposed in cases of non-compliance.
- G. Ensure the possibility of continued adult education and vocational training for students in the adapted school system.

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<sup>&</sup>lt;sup>180</sup> Swedish National Union of Students Kartläggning stöd 2023

<sup>&</sup>lt;sup>181</sup> HejaOlika Folkhögskolor 2023

<sup>182</sup> Swedish National Council of Adult Education Budget 2023 /

<sup>183</sup> Sydsvenskan Villkor för barn med funktionsnedsättning 2023

<sup>184</sup> SOU2023:96

#### **Article 25 Health**

110 At the group level<sup>185</sup>, persons with disabilities report poorer living conditions, unhealthy lifestyles, and worse health<sup>186</sup> compared to the general population. In many areas that promote public health, individuals with disabilities face worse conditions<sup>187</sup> than the general population. Significant differences exist in access to healthcare between regions.

111 The risk för suicide is still increasing for young persons<sup>188</sup> with several studies including proposals from young persons to improve mental health<sup>189</sup>. Public agencies presented a proposal for a strategy in September 2023 for mental health and suicide prevention<sup>190</sup>.

112 Persons with disabilities risk later diagnosis and treatment, and thus a poorer prognosis for recovery in serious illnesses. <sup>191</sup> Women receiving services according to LSS are at almost double the risk of dying from breast cancer compared to other breast cancer patients. Persons with chronic mental illness who suffer a stroke receive neck surgery to a lesser extent compared to other stroke patients.

113 Life expectancy is also expected to be shorter among persons with certain disabilities, for example, among individuals with autism<sup>192</sup>, the life expectancy is 16 years shorter, and among those with mental health issues<sup>193</sup>, the expected life expectancy is between 10-20 years shorter than in the general population.

114 Children and young persons<sup>194</sup> with disabilities also report<sup>195</sup> being less satisfied with life, having poorer self-rated health, and more self-reported health issues than other children.

115 A recent survey<sup>196</sup> of the health status of persons with mental disabilities showed that common somatic conditions such as diabetes,

<sup>&</sup>lt;sup>185</sup> FHM Hälsa funktionsnedsättning 2023

<sup>&</sup>lt;sup>186</sup> SCB Statistik funktionsnedsättning 2022 /

<sup>187</sup> FHM Hälsa funktionsnedsättning 2023

<sup>188</sup> FHM Statistik Suicid

<sup>&</sup>lt;sup>189</sup> FHM Ungas psykiska hälsa

<sup>&</sup>lt;sup>190</sup> FHM Suicidstrategi

<sup>&</sup>lt;sup>191</sup>SoS Insatser och stöd 2019

<sup>&</sup>lt;sup>192</sup> Autism Registerstudie om livslängd

<sup>193</sup> NSPH Leva med psykisk ohälsa

<sup>&</sup>lt;sup>194</sup> FHM Barn med funktionsnedsättning 2021-2022

<sup>&</sup>lt;sup>195</sup> FHM Press release Unga med funktionsnedsättning 2023

<sup>&</sup>lt;sup>196</sup> SoS2023-10-8755

obesity, and Chronic obstructive pulmonary disease, COPD were up to five times more common in this group compared to the general population. Oral health was also worse than in the general population. Similarly, the risks of self-harm, suicide, and death from other causes than suicide were significantly higher within this group compared to the general population.

116 A ten-year strategy in the field of mental health and suicide<sup>197198</sup> was launched in the fall of 2023, but without sufficient resources, it will not be able to be implemented.

117 There are significant issues concerning the situation and the lack of data regarding sexual and reproductive health and rights<sup>199</sup> for persons with disabilities.

118 Persons with disabilities are more severely affected than other groups in health crises, as could be observed during the COVID-19 pandemic, when the mortality rate from the virus was as high as  $6.8^{200}$  percent among persons receiving personal assistance. This is explained by both increased susceptibility to the virus in certain conditions and inadequate crisis management, particularly regarding infection control measures.

119 During the ongoing pandemic and in the aftermath of the economic downturn, where healthcare is forced to make difficult choices, a highly concerning discussion<sup>201</sup> has arisen about healthcare prioritization based on the assessment of biological age<sup>202</sup>.

## **Recommendations article 25**

A. Develop a national action plan to continuously identify and address inequalities in health, including sexual and reproductive health, healthcare, health services and dental care linked to disability.

<sup>&</sup>lt;sup>197</sup> FHM Nationell strategi

<sup>&</sup>lt;sup>198</sup> MFD Ny strategi psykisk hälsa

<sup>199</sup> RFSU Vill du ligga med mig då

<sup>&</sup>lt;sup>200</sup> SoS2021-8-7520

<sup>&</sup>lt;sup>201</sup> TV4 Vården måste välja bort patienter 2023 -

<sup>&</sup>lt;sup>202</sup> SKR Prioriteringar vårdresurser

- B. Monitor equal access to health and healthcare in all regions based on disability disaggregated data and intersectional perspective.
- C. Take immediate actions to eliminate discriminatory structures that affect differences in survival rates in somatic healthcare.
- D. Ensure disability rights perspective in the strategy for mental health and suicide prevention, with follow up of outcomes.

## Article 26 Habilitation and rehabilitation

120 There are significant differences concerning rehabilitation, habilitation, and aids for persons with disabilities between the regions<sup>203</sup>, when it comes to the provision of services and the quality of services related to endurance and intensity. As the organization, agreements, and distribution of responsibilities between the principals around rehabilitation and habilitation vary across the country, achieving equivalence is impossible.

121 There is a lack of statistics and surveys in the areas of rehabilitation and habilitation, both nationally and regionally. Comparisons and follow-ups are therefore difficult to conduct. Stakeholders believe that it is a challenge and that it can affect access to rehabilitation and habilitation, for example, different aids.

## **Recommendations article 26**

- A. Monitor and ensure equal access to qualified rehabilitation and habilitation across the country.
- B. Urgently introduce national guidelines for rehabilitation, habilitation, and aids to achieve equivalence across the country.

# **Article 27 Work and employment**

122 The labour market policy for persons with disabilities is severely neglected. Since 1980, when wage subsidies for employers were introduced and Samhall <sup>204</sup> was founded, no significant reforms have

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<sup>&</sup>lt;sup>203</sup> SoS 2023-2-8373

<sup>&</sup>lt;sup>204</sup>Samhall Sweden's largest company owned by the state

been implemented. In 2021, organisations of persons with disabilities joined together<sup>205</sup> in a proposal with 73 measures sent to the government, 22 of these directly related to article 27<sup>206</sup>. Another part focuses on the situation for refugees with disabilities where the situation has become worse after new government decisions in 2023 (see article 18).

123 About 81 percent of the population state that they have work. For persons with "reduced ability to work", about 44 percent<sup>207</sup>, with more men (51 percent) than women (39 percent) state that they work<sup>208</sup>. Every third person with disability faced discrimination at work. The data collection has changed over time making it difficult to compare.<sup>209</sup>

124 There are targets to increase gender equality and persons born outside Sweden but not for disability in public employment<sup>210</sup>. The government replied<sup>211</sup> to question why, by referring to requirements in the constitution for "merit and competence" in government administration<sup>212</sup>.

125 The apprenticeship program 2016-2023 for public agencies covering persons with disabilities and "newcomers" reached 100 pwd in 2022 (target 500)<sup>213</sup>.

126 It has become more difficult to get support for employment. It is reported that the assessment process for "reduced capacity to work", needed to get support from the Employment Agency for persons with disabilities, takes on average about one year to complete<sup>214</sup>.

127 Budget allocations to The Swedish Public Employment Agency have been reduced since 2019, while the budget for Samhall increased for 2024<sup>215</sup> despite severe criticism from the national audit office. <sup>216</sup> In

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<sup>&</sup>lt;sup>205</sup> List of OPD:s 73-punktsprogram

<sup>&</sup>lt;sup>206</sup> OPD <u>75-punktsprogram</u> p.10 – 15

<sup>&</sup>lt;sup>207</sup> SCB <u>Var tredje person med funktionsnedsättning har diskriminerats i arbetslivet</u> (scb.se)

<sup>&</sup>lt;sup>208</sup> SCB <u>Labour market for pwd</u>

<sup>&</sup>lt;sup>209</sup> SCB Förutsättningar I arbetslivet Page 121

<sup>&</sup>lt;sup>210</sup> State Budget Section 4.1 p.41

<sup>&</sup>lt;sup>211</sup> Skriftligt svar till Funktionsrätt Sverige från Lena Micko October 2020

<sup>&</sup>lt;sup>212</sup> Instrument of government Chapter12 § 5

<sup>&</sup>lt;sup>213</sup> Swedish Agency for Public Management Uppföljning praktikplatser 9

<sup>&</sup>lt;sup>214</sup> Almega <u>Så bryter vi långtidsarbetslösheten</u> Diagram 6

<sup>&</sup>lt;sup>215</sup> Government Post Budget Bill 2024

<sup>&</sup>lt;sup>216</sup> National Audit Office RiR2023:14

December 2023 the government announced an overview of Samhall<sup>217</sup>, but still no initiative to ensure dialogue and timely access to reasonable accommodation in line with the recommendations from the CRPD committee communication no  $45/2018^{218}$  (apart from publishing the communication on the web).

128 Municipalities may retrieve state funding for "Daily activities for persons with intellectual disabilities" (LSS), The activity is not covered by Swedish labour market legislation and work environment regulations.

129 About 1 in 10 of all young persons 16-29 years old are neither working nor studying for a year. Many of these young persons have a disability or are waiting for a diagnosis needed to receive support, and they remain longer without work och studying. Support is supplied by municipalities on a voluntary basis— with big differences across the country.<sup>219</sup>.

130 A government inquiry has started, to limit the overall level of income benefits and allowances for households and "increase incentives for employment. Disability is mentioned, but not the increased risk for poverty<sup>220</sup>.

### **Recommendations article 27**

- A. Set goals and establish a national action plan for employment in the public sector, with review of the constitution if considered necessary.
- B. Include OPD:s in a full review the labour market policy in support for persons with disabilities, ensuring access to personal and individualized support with adequate funding, in an inclusive process taking age, gender and intersectionality into account.
- C. Establish adequate and equal support across the country, including adapted vocational guidance and internships, for

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<sup>&</sup>lt;sup>217</sup> Government Skr2023/24:51

<sup>&</sup>lt;sup>218</sup> <u>CRPD/C/23/D/45/2018</u> Para 9

<sup>&</sup>lt;sup>219</sup> MUCF Fokus 23

<sup>&</sup>lt;sup>220</sup> Dir2023:70

young persons with disabilities who are neither working nor studying.

# Article 28 Adequate standard of living and social protection

131 The risk for poverty for persons with disabilities has increased at a fast rate in Sweden compared to other EU countries<sup>221</sup> for decades when the social benefits have decreased<sup>222</sup>. The purchasing power for households with children and two average income earners increased by 74 percent 1992-2018, compared to a single parent on sickness benefit at the guaranteed level increased by 7 percent<sup>223</sup>. The last years there have been high inflation. <sup>224</sup>.

132 The maximum "activity compensation for reduced work capacity" <sup>225</sup> only covers about 93 percent of reasonable living costs <sup>226</sup> calculated by the Swedish Consumer Agency before taxes <sup>227</sup>. Tax is higher for beneficiaries than for persons with employment. Additional and rising costs for adults with intellectual disabilities <sup>228</sup> make many dependent on relatives to cover rising costs for housing etc.

133 Difficult to qualify for sickness- and activity support with administrative burden to apply for support<sup>229</sup> and local differences are common.<sup>230</sup>. 1 in 5 of persons denied activity support are contacted by the Enforcement Authority<sup>231</sup>. An increasing number, 40 percent are forced to apply for livelihood support<sup>232</sup>, a benefit designed for temporary support.

134 Proposals from a government inquiry to analyse and monitor economic equality for persons with disabilities have not been

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<sup>&</sup>lt;sup>221</sup> EDF <u>Human Rights Report Issue 4</u>

<sup>&</sup>lt;sup>222</sup> FK Social Insurance in Figures 2023 p.16

<sup>&</sup>lt;sup>223</sup> ISF2022:2 p 5 and 6

<sup>&</sup>lt;sup>224</sup> FK Socialförsäkringen vid hög inflation (forsakringskassan.se)

<sup>&</sup>lt;sup>225</sup> FK Activity Compensation

<sup>&</sup>lt;sup>226</sup> Consumer Agency Necessary costs for households

<sup>&</sup>lt;sup>227</sup> FUB, Fångad i Fattigdom, (forthcoming) 2024, p.19

<sup>&</sup>lt;sup>228</sup> SOU2021:14 p.95, last para section 6.3.1

<sup>&</sup>lt;sup>229</sup> European Commission, <u>Social protection for pwd</u> p. 65, 87 search Sweden for more data.

<sup>&</sup>lt;sup>230</sup> SoS <u>Annual report support services</u> 2023

<sup>&</sup>lt;sup>231</sup> SVT News article

<sup>&</sup>lt;sup>232</sup> ISF 2021:2

implemented<sup>233</sup>. A new governmental inquiry to "strengthen the financial security of persons who have sickness benefit or activity benefit by ensuring an appropriate calculation of the benefits" <sup>234</sup> was planned and started in September 2022, but was cancelled by the new government in December 2022.

### **Recommendations article 28**

- A. Ensure implementation of article 28 and SDG:s to reduce the risk for poverty and stop further regression by measure to ensure financial security for persons with disabilities who cannot work.
- B. Ensure accessible information and application systems for support to persons with disabilities, decisions and complaints mechanisms, applicable to the Swedish Social Insurance Agency and municipal level.

# Article 29 Participation in political and public life

135 Amendments in the election law about assistance to persons with disabilities in the polling place<sup>235</sup> but still persons with disabilities cannot vote for different reasons, for example lack of information from guardians or support to get to the polling place<sup>236</sup>. Planned government inquiry on secret voting was cancelled 2022<sup>237</sup>.

136 There is no systematic process for incident reporting and follow up when persons with disabilities cannot vote<sup>238</sup>. Wrong material in braille was sent out at elections 2022<sup>239</sup>.

137 Checklist for accessible polling places developed by the Swedish Agency for Participation<sup>240</sup> is voluntary, and there are different local measures.

<sup>&</sup>lt;sup>233</sup> SOU2022:4 p. 40

<sup>234</sup> Dir2022:62

<sup>235</sup> SOU2021:96

<sup>&</sup>lt;sup>236</sup> Swedish Disability Rights Federation Hinder att rösta i valet 2022

<sup>&</sup>lt;sup>237</sup> SRF Valhemlighet ska gälla alla 2022

<sup>238</sup> DO Referral SOU2021:96

<sup>&</sup>lt;sup>239</sup> Election Authority Web post 2022

<sup>&</sup>lt;sup>240</sup> MFD Checklista för tillgängliga val

138 Challenges for politicians with disabilities include lack of accessibility and double costs for travel<sup>241</sup>.

139 A survey in cooperation with Public Service Broadcaster to persons with disabilities after general elections 2022<sup>242</sup>, showed that 1 in 4 said they had not received adequate information to decide how to vote. 96 percent of them said that media did not raise issues that matter to them<sup>243</sup>.

140 There is no disaggregated data for disability and national follow up of SDG 16.7.1 and 16.7.2<sup>244</sup>

### **Recommendations article 29**

- A. Enforce legislation with high standard accessible polling stations all over the country with easy to find complaint mechanisms for systematic follow-up, sanctions and amendments.
- B. Implement incident reporting when persons with disabilities cannot vote, with systematic follow up and remedies.
- C. Start an inquiry about power/influence in society for persons with disabilities and other disadvantaged groups as proposed in 2014 to establish measures and follow up related to SDG 16.7.2.

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

141 Persons with disabilities do not have<sup>245</sup> the same opportunities to engage in cultural and recreational activities compared to the rest of the population. The Swedish Arts Council (Statens kulturråd) sets accessibility requirements<sup>246</sup> for activities receiving state funding, but these requirements are not effectively monitored.

142 Young persona with disabilities participate in sports and physical activities significantly less than others in the same age group. Research

<sup>&</sup>lt;sup>241</sup> EDF <u>Human Rights Report Issue 6</u> Page 42

<sup>&</sup>lt;sup>242</sup> Swedish Disability Rights Federation Election survey 2022

<sup>&</sup>lt;sup>243</sup> Swedish Disability Rights Federation Funktionsrättsfrågor I valet 2022

<sup>&</sup>lt;sup>244</sup> SCB <u>Agenda 2030 Goal 16</u>

<sup>&</sup>lt;sup>245</sup> MFD <u>Aktiv fritid</u> 2020

<sup>&</sup>lt;sup>246</sup> Swedish Arts Council <u>Tillgängligt kulturliv</u>

shows<sup>247</sup> that this is due to a lack of knowledge, resources, and inclusion. A government investigation concludes<sup>248</sup> that there is no coherent national structure for promoting physical activity, particularly for persons with disabilities. One of the recommendations from the investigation is to amend the Health and Medical Services Act to include the right to assistive devices for leisure activities.

## **Recommendations article 30**

- H. Develop national accessibility guidelines and monitor access for all in publicly funded culture and sports at the state, regional, and municipal levels.
- I. Ensure and monitor access to playgrounds, recreational activities, physical education classes in pre-schools and schools for children with disabilities. Eliminate regional disparities and differences between boys and girls to guarantee the physical health and social inclusion of all children.

# Specific Obligations (Arts. 31–33)

## Article 31 Statistics and data collection

143 The questions to identify disability have been changed several times in relation to Eurostat making comparisons difficult<sup>249</sup>. The government says that data from employment statistics will not be comparable with earlier years<sup>250</sup>. The percentage of persons with disabilities dropped to 10 percent<sup>251</sup>. No analysis has been found about the impact to follow up SDG:s or outcomes related to implementation and monitoring of the CRPD.

144 Statistics Sweden made a special report related to the SDG:s 2020<sup>252</sup>, but the latest national follow up of SDG:s indicators does not include disability data, even when data exists for discrimination, SDG 10<sup>253</sup>.

<sup>&</sup>lt;sup>247</sup> Centrum för idrottsforskning Aktiva och inaktiva i skola och på fritid

<sup>&</sup>lt;sup>248</sup> SOU2023:29

<sup>&</sup>lt;sup>249</sup> SCB Fråga för att mäta funktionsnedsättning

<sup>&</sup>lt;sup>250</sup> State Budget 2023, p.109

<sup>&</sup>lt;sup>251</sup> SCB <u>Labour market for persons with disabilities</u> 2023 /

<sup>&</sup>lt;sup>252</sup> SCB Leaving no one behind.

<sup>&</sup>lt;sup>253</sup> SCB Status report 2022 Agenda 2030 p.23

145 The government has asked Statistic Sweden to review methods to collect data on living conditions, including use of "register data" for persons receiving benefits. A report is due 31st January. <sup>254</sup> Statistics Sweden takes up budget restraints as a barrier for data collection. <sup>255</sup>

146 OPD:s are not involved in indicators to follow up outcomes of Disability Policy despite suggestions to get inspiration from UN resource package. For example, the government still uses number of new accessibility measures for bus stops as an indicator to show progress<sup>256</sup>.

147 The lack of disaggregated data has been raised, for example in relation to violence by MFD<sup>257</sup>. The lack of data from persons with disabilities living in "special housing", or persons with mental health or cognitive disabilities or refugees have not been addressed.

148 Issues with lack of disaggregation on local government has not been addressed. Different methods are used preventing tools to ensure equal treatment wherever you live.

149 The National Audit office has criticised the government for not following up shortcomings of the responsible agency for statistics in schools<sup>258</sup> and a report from an inquiry was presented the 15<sup>th</sup> of December<sup>259</sup>.See also article 24.

### **Recommendations article 31**

- A. Develop procedures for coordinated systematic collection of disaggregated data including the diversity of disabilities to allow intersectional analysis and follow up outcomes of measures across the whole country to implement the convention.
- B. Establish indicators, in an inclusive process with OPD:S, to enable monitoring of implementation and outcomes for equitable comparisons related to indicators concerning human rights for

<sup>&</sup>lt;sup>254</sup> SCB Statistik om levnadsförhållanden för personer med funktionsnedsättning

<sup>&</sup>lt;sup>255</sup> SCB, <u>Budget proposal 2022-2024</u> p.32

<sup>&</sup>lt;sup>256</sup> Government State Budget 2024, p.111

<sup>&</sup>lt;sup>257</sup> MFD, Våld mot personer med funktionsnedsättning 2023 p.43

<sup>&</sup>lt;sup>258</sup> Government Communication 2022/23:76

<sup>&</sup>lt;sup>259</sup> Dir2022:73

persons with disabilities, taking into account both the CRPD and Agenda 2030.

# **Article 32 International Cooperation**

150 In November 2022 the government decided on budget restrictions in payments for international development<sup>260</sup>. New direction for development with closer link to trade, and rebuilding Ukraine<sup>261</sup>, although important, United Nations Association Sweden had already raised negative impact on poor and disadvantaged persons in other parts of the world<sup>262</sup>.

151 Disability is not mentioned in the Strategy for Sweden's humanitarian aid provided through the Swedish International Development Cooperation Agency (Sida) 2021–2025<sup>263</sup>. There is no disability focal point at SIDA<sup>264</sup>.

152 According to SIDA, the OECD-DAC marker for disability shows that 0.25 percent of all efforts in 2022 had disability as a primary purpose.<sup>265</sup>

## **Recommendations article 32**

Ensure inclusion of Disability Rights by a twin track approach that can be monitored for outcomes by:

A. Designate a disability focal point tasked to establish "smart" objectives for inclusion of disability rights and explicitly include the target group "persons with disabilities" in strategies and

<sup>261</sup> Government web 15 December 2023

<sup>&</sup>lt;sup>260</sup> SIDA communication April 2022

<sup>&</sup>lt;sup>262</sup> Swedish United Nations Association, Web Budget cuts article 2023

<sup>&</sup>lt;sup>263</sup> Government Strategy for Sweden's humanitarian aid provided through the Swedish International Development Cooperation Agency (Sida) 2021–2025 Search word disability

<sup>&</sup>lt;sup>264</sup>Hudson, Master thesis, <u>Disability Discomfort in Development</u>, 2023 Page 14, 41 and 58

<sup>&</sup>lt;sup>265</sup> Information received in email to OPD, it is not published on the web. See also figure 2 <u>Tracking disability inclusive development: Making the most of the OECD-DAC disability inclusion policy marker to promote equality and inclusion in international development and humanitarian assistance.</u>

- policies to increase the number of targeted measures for persons with disabilities ensure a twin track approach.
- B. Developing specific requirements with disaggregated data and an intersectional approach for authorities and stakeholder working with international development to increase knowledge about disability rights in development and humanitarian work.

# Article 33 National Implementation and Monitoring

153 Recommendations from the CRPD committee have been spread but none fully implemented, apart from establishing a National Human Rights Institution.

154 The government emphasized in 2022 focus on "Integrating the disability rights perspective into more political and societal areas remains a focus." 266. However, the government does not mention the term coordination mechanism in any CRPD report. The only focal point is still located at the ministry of Social Affairs. The same department administrates the interdepartemental working group, described in reply to question 1 e) LoIPR.<sup>267</sup>

155 The human rights approach is not elaborated in disability policy. The government does not mention the ministry of Social Affairs as one of the responsible ministries for national policy related to democracy and human rights on the website<sup>268</sup>.

156 There is no formal role for OPD:s to ensure active involvement in decision-making and monitoring in line with general comment 7. The need for enhanced dialogue with Civil Society Organisations in reporting and implementation of human rights was highlighted in the report to CESCR 2021<sup>269</sup>. A working group with CSOs, including OPD:s, County Administrative Board and the Ministry of Social Affairs drafted a proposal to move from ad hoc towards a systematic national mechanism for reporting and follow up<sup>270</sup>. The meetings stopped after the change of government in 2022.

<sup>&</sup>lt;sup>266</sup> Government policy statement 2022

<sup>&</sup>lt;sup>267</sup> CRPD/C/SWE/CO/2-3

<sup>&</sup>lt;sup>268</sup> Government web page Democracy and Human Rights, Collected 2023-10-30

<sup>&</sup>lt;sup>269</sup> Government Reply to LoIPR on CESCR received 1 November 2021 Para 2

<sup>&</sup>lt;sup>270</sup> OHCHR National Mechanisms for reporting and follow up

157 Disability policy is delegated to public agencies without mandate to change legislation and policy. The Swedish Agency of Participation "fulfils its mission by monitoring and analysing developments, proposing methods, guidelines and guidance, disseminating knowledge and initiating research and other development work as well as providing support and proposing measures to the government" 271

158 Sweden has been without a national monitoring mechanism to **promote**, **protect and monitor** the implementation of the CRPD since 14th of January 2009 when the CRPD entered into force. A government inquiry from 2009 on how to fulfil article 33.2 establishing the need for individual and general complaints to "protect" 272 was left without any action. In 2022 the Swedish National Human Rights Institution was established with the task to constitute the national monitoring mechanism, but without the mandate to handle individual complaints.

159 The NHRI does not have the mandate to consider individual or group complaints, nor referring cases to the courts and participating in judicial proceedings and they do not maintain databases with information on practices related to the implementation of the Convention in line with the Guidelines for independent monitoring mechanisms<sup>273</sup>. Some issues related to article 33.2 were raised in November 2023 at high level conference about the application to the Global Alliance of National Human Rights Institutes, GANHRI, for Astatus. Concerns were expressed from the Office for Democratic Institutions and Human Rights, OSCE and CSO:s about the limited mandate that does not include individual complaints, independence and CSO involvement<sup>274</sup>.

160 The lack of protection, access to justice and enforcement of rights have been raised by the CEDAW committee<sup>275</sup> and the CRC committee<sup>276</sup> with several recommendations about the need for individual complaint mechanism.

161 The government points to many different organisations<sup>277</sup> for individuals to claim their human rights. It makes it difficult for the

<sup>&</sup>lt;sup>271</sup> Sweden Common Core Document Para 135 (and 94)

<sup>&</sup>lt;sup>272</sup> SOU2009:36 p.41

<sup>&</sup>lt;sup>273</sup> CRPD/C/1/Rev.1</sup> Annex para 13

<sup>&</sup>lt;sup>274</sup> OSCE, Opinion NHRI-SWE/476/2023 Section 5.2 para 45-47 complaints

<sup>&</sup>lt;sup>275</sup> CEDAW/C/SWE/CO/10 42 a

<sup>&</sup>lt;sup>276</sup> CRC/C/SWE/CO/6-7 See 12 c, 23 d and 26 b

<sup>&</sup>lt;sup>277</sup> Government web, Om dina rättigheter kränks, collected December 2023

individual, and for the state to find data, amend and learn from complaints. The lack of judicial enforcement of the CRPD by individuals and groups is a combination of lack of a systematic implementation of the CRPD in legislation (article 4), barriers regarding action to justice (article 13) and the lack of judicial tools for the monitoring mechanism to protect.

162 The institute shall "work in close cooperation with the Swedish Agency for Participation" according to the government bill<sup>278</sup> even though that it is not an independent agency, in line with para 14 of the Guidelines for independent monitoring mechanisms<sup>279</sup>.

163 Organisations of Persons with Disabilities may propose members of the NHRI council, but not to the board. There is no formal permanent body representing organisations of persons with disabilities in the monitoring framework as for example in Spain<sup>280</sup>. For funding of OPD:s see article 4.

## **Recommendations article 33**

- A. Ensure effective governance and coordination within the government and parliament based on Article 33.1. Create resources and political commitment across the country.
- B. Review the budget and status of a coordination mechanism to implement the convention. Consider placing it in the ministry responsible for other human rights conventions, and ensure inclusion of OPD:s and several focal points in the government including the County Administrative Boards.
- C. Implement a structured plan to implement recommendations from the CRPD committee and other UN treaty bodies, including OPD:s
- D. Re-examine an independent framework to effectively protect and monitor the implementation of the convention involving OPD;s

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<sup>&</sup>lt;sup>278</sup> Prop2020/21:143 Page 57 last para section 7.9

<sup>&</sup>lt;sup>279</sup> Irish Human Rights Commission <u>Establishing a Monitoring Framework in Ireland</u> for the <u>UNCRPD</u> 2016 p.27

<sup>&</sup>lt;sup>280</sup> Irish Human Rights Commission <u>Establishing a Monitoring Framework in Ireland</u> for the UNCRPD 2016 p. 21

- E. Establish a complaint mechanism for reports of violations of the CRPD for individuals and organisations of persons with disabilities with age-appropriate accommodations to enable monitoring of the rights.
- F. Ensure legal involvement and funding in line with General Comment 7 in collaboration with the disability movement, for active involvement in the implementation and monitoring of the convention.