

National CRPD monitoring mechanism in Sweden

Supplementary information to the UN Committee on the Rights of Persons with Disabilities

Regarding the 2nd/3rd State party
review procedure of Sweden 2024



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1. Introduction

The Swedish Institute for Human Rights was established on 1 January 2022. The Institute is designated to perform the functions of an independent national mechanism under Article 33(2) of the UN Convention on the Rights of Persons with Disabilities (CRPD).

This report is the Institute's written contribution to the UN Committee on the Rights of Persons with Disabilities' review of Sweden in 2024. The Institute's report does not reflect all challenges within the scope of the CRPD. Consequently, submissions from other actors, especially organisations of persons with disabilities, constitute important sources.

2. Summary

2024 marks 15 years since the CRPD entered into force in Sweden. In some areas, progress has been made. However, the paradigm shift which stands at the heart of the Convention has yet to be fully implemented and several of the general commitments and specific rights have not been realised. This applies, for example, to preconditions for self-determination, participation, health, education, work, leisure, democracy and freedom. In some respects, there have been set-backs.

In Sweden, the living conditions of persons with disabilities are still generally worse than those of the rest of the population. Education levels are lower, unemployment is higher, economic vulnerability is greater and physical and mental health are poorer. Access to individualised support is limited and the preconditions for real self-determination and full participation in society are lacking. The individual's full legal capacity is not sufficiently protected and persons with disabilities remain subject to various forms of coercion and limitations in health care and social support. They are also more exposed to various forms of violence at home, at school, at the workplace and on the Internet. Since the CRPD Committee's last review in 2014, inequality has increased in several areas and discrimination is reported to a greater extent.

Structures that are segregating by nature remain significant elements of the systems aimed at meeting the needs of persons with disabilities in areas such as housing, education and employment. In the case of specific forms of housing, there are clear institutional features in some establishments, including coercion, limitations and violence. There is insufficient consideration of the design of the systems from a human rights perspective.

Persons with disabilities also testify to a partial return of the medical model where the person's own needs, interest and right to self-determination are not respected. The social security and disability support systems require extensive medical evidence and persons with disabilities describe feelings of being mistrusted and treated as a burden, rather than being considered as individuals with rights and the capacity to make valuable contributions to society.

Sweden needs to raise the level of ambition in the implementation of the CRPD and, to a greater extent than today, conduct structured and systematic efforts to ensure the rights of the Convention.

3. Observations and recommendations by the Institute

In this section, the Institute highlights several areas where Sweden must increase its efforts to fulfil its obligations under the CRPD. The Institute also provides suggestions on what recommendations the CRPD Committee can make to Sweden during the review in 2024. The Institute emphasizes the State's obligation to involve persons with disabilities in all measures although this is not mentioned in each of the recommendations made by the Institute.

Articles 1–4

General principles and obligations

Deficiencies in legislative and judicial impact

1. Like most conventions to which Sweden has acceded, the CRPD has not been incorporated into Swedish law. Nor has there been any systematic review of the conformity of legislation and enforcement with the CRPD since its ratification in 2008. Such a review is needed to strengthen the legal and practical protection of rights and would be an important tool for increasing the transposition of the Convention into Swedish law. The need for such a review becomes particularly clear in light of the rapid pace of legislation that has characterised several areas of relevance to the rights of persons with disabilities, such as migration, penal policy and social security.
2. Currently there is no regulation requiring the CRPD and consequences for the rights of persons with disabilities to be considered in the legislative and budgetary processes. It is also rarely a requirement in specific commissions of inquiry.
3. Analyses show that the use of treaty-compliant interpretation is limited in Swedish courts and authorities.

Lack of coherent strategic efforts to implement the Convention

4. In 2019, a government commission of inquiry concluded that a cross-sectoral issue such as disability policy, poses challenges in terms of governance. No individual actor can achieve the objectives on their own. The commission found that societal efforts needed to be coordinated to ensure coherence. In accordance with the principle of responsibility and funding, all sectors of society are responsible for implementing the national disability policy. To realise these ambitions, however, authorities must be provided with guidance on compliance and sufficient resources must be allocated. The national strategy, adopted in 2021, focuses on follow-up rather than implementation, and it emphasises the general responsibility of each sector for implementing the national disability policy. The system for progressive realisation is flawed. The Agency for Participation (MFD) has been assigned the responsibility for monitoring how authorities, municipalities and regions work to improve accessibility and remove barriers, but the Agency does not have the mandate to direct the work of these actors. In the Institute's opinion, Sweden's current system does not meet the need for governance and coordination that has been identified in this area.
5. The 2021 strategy states that a national action plan should be adopted by 2026. Given what is already known about the shortcomings in relation to the rights of persons with

disabilities, the Institute regrets this delay. The need for prompt action towards clear and strategic governance in this area becomes particularly evident in the light of the results of a nationwide survey concerning the work of municipalities and regions. It shows that disability policy work is not always a political priority, and that there is a risk of it being de-prioritised when security policy, crisis preparedness and law enforcement are high on many agendas. The economic situation with high inflation also places extensive pressure on the budgets of municipalities and regions.

Need for improved follow-up on recommendations by the Committee

6. There is a lack of systematic and transparent follow-up of the Committee's previous recommendations. Many shortcomings identified in 2014 remain. Involvement of persons with disabilities has been insufficient.

Insufficient involvement of persons with disabilities and their organisations

7. Studies and descriptions by persons with disabilities demonstrate that the forms of involvement used at the national, regional and local levels do not always meet the requirements of the Convention. Stakeholders describe that their views and suggestions are not always heard, that they are involved too late in the decision-making processes and that there is no feedback on how their views have been taken into account. Among other things, they describe insufficient involvement in the development of the national strategy for systematic monitoring of disability policy.
8. Government grants to the disability rights movement lack annual indexation. The disability rights movement points to a need for increased resources to enable the organisations to operate independently and effectively.

Need for greater competence on disability rights and intersectional perspectives in the public sector

9. Both politicians and civil servants in municipalities and regions lack awareness of disability rights, accessibility and active involvement. Often there is a lack of knowledge about how disability rights and intersectional methods can be integrated into specific and cross-sectoral work. The situation, which is highlighted by both disability rights organisations and by public actors, is said to be reducing the drive of disability policy issues at the municipal and regional level.

Separate structures are used in several areas

10. Separate structures are used for some persons with disabilities in education, employment and housing. These include adapted schools, sheltered workshops and particular living arrangements (combined housing and support). The aim of these structures is to improve preconditions and outcomes, but risk contributing to isolation and segregation, not least for persons with autism and intellectual disabilities. In order to counteract segregation related to disability, these structures need to be reviewed and proposals need to be submitted on how a transition to integrated systems that fulfil needs and rights can be made.

Recommendations

11. Adopt a national strategy and action plan for the implementation of the CRPD with measurable targets, indicators, division of responsibilities and follow-up mechanisms.
12. Initiate an in-depth review of the conformity between Swedish law and the CRPD.
13. Introduce regulations that establish the obligation to account for the impact of legislative proposals on the implementation of the CRPD. Provide methodological support for making such analyses.
14. Act to increase knowledge within courts and authorities about the CRPD and how to ensure treaty-compliant interpretation in proceedings and decisions. Ensure the obligation to use the maximum of available resources to fulfil the economic, social and cultural rights under the CRPD.
15. Act to increase knowledge about disability rights in the public sector.
16. Ensure the obligation to use the maximum of available resources to fulfil the economic, social and cultural rights under the CRPD.
17. Establish a procedure for more systematic and transparent follow-up of the recommendations of the CRPD Committee.
18. Review the conditions and modalities for involvement of persons with disabilities at national, regional and municipal levels, based on the normative content of Articles 4(3) and 33(3) and the Committee's General Comment No 7 on meaningful participation of persons with disabilities and their representative organisations.
19. Assess whether the rights of persons with disabilities are ensured through current structures and practices related to education, individual and financial support, housing and employment, with a particular focus on the right to non-discrimination, self-determination and full participation in the community. This assessment should evaluate the overall impact of the current systems from a life perspective, including risks that

the structures segregate persons with disabilities. The task should include identifying obstacles to the realisation of rights.

Article 5

Equality and non-discrimination

Protection against discrimination needs to be strengthened

20. Complaints concerning disability-based discrimination have increased in recent years. Most complaints are received within the area of education. Other recurring areas are goods, services and social services.
21. The Discrimination Act does not protect fully against all forms of discrimination that the State Party should prohibit according to the CRPD. The protection against discrimination in the form of inadequate accessibility does not cover the whole public sector, nor does it cover housing. It is not ensured that the requirement of reasonable accommodating measures in working life is respected in practice. Sweden has not acted to implement the conclusions of Communication No. 45/2018 R.S. v Sweden about ensuring opportunities for individual compensation. The Institute considers that there is also a need to intensify measures to combat intersectional discrimination.
22. The number of investigations carried out by the Equality Ombudsman (DO) regarding reported acts of discrimination have increased significantly in recent years. However, there are several practical and economic obstacles hindering effective pursuit of discrimination claims in or out of court. Organisations have no independent standing in cases where the claim has not been raised by an individual, e.g. cases relating to accessibility within an establishment or in relation to ableist public statements in advertising or media. Neither individuals nor the Equality Ombudsman have legal means to compel an entity to stop the discriminating practice. Furthermore, the risk of having to reimburse the defendant's legal costs may deter persons with disabilities from initiating and effectively pursuing discrimination proceedings.

Insufficient protection against hate crime

23. Disability based hate crime is not explicitly criminalised. There is not enough data and knowledge about disability-based hate crime.

Recommendations

24. Review the Discrimination Act to strengthen protection against discrimination of persons with disabilities, including intersectional discrimination.
25. Provide explicit protection against disability-based hate crimes and gather statistics on its occurrence.

Article 6

Women with disabilities

Inequality and insufficient measures relating to women's health

26. The physical and mental health of women with disabilities is poorer than both that of men with disabilities and of women in general.
27. Few specific measures have been taken to improve the health of women with disabilities and those that exist focus primarily on antenatal and natal care and sexual health. However, the inequalities that characterise the health of women with disabilities are not limited to these areas. Furthermore, there are still differences in treatment between regions and between different groups of women.

Need to improve the economic conditions for women with disabilities

28. Studies show that women with disabilities have less favourable economic conditions both compared to men with disabilities and to women and men in the rest of the population. They have more limited access to the labour market and are more often part-time unemployed or have hourly contracts. The proportion of women enrolled in the Swedish Public Employment Service receiving support from the agency is significantly lower than the proportion of men.
29. Initiatives have been taken by the Government to enable identification of financial gender disparities among persons with disabilities. This is an important step but, on the basis of this knowledge, active measures are also needed to strengthen the economic conditions for women with disabilities.

Recommendations

30. Act and allocate resources to strengthen the health of women with disabilities. Actions should be based on knowledge about barriers and risks of discrimination particularly affecting women with disabilities in their use of healthcare services.
31. Act to increase labour market participation of women with disabilities, including addressing inequalities in labour market support.

Article 7

Children with disabilities

Lack of participation and use of the principle of the best interests of the child

32. Surveys point to shortcomings in participation and the principle of the best interests of the child in matters related to disability support and interventions from sectors of the social services where there is an over-representation of children with disabilities.
33. The UN Committee on the Rights of the Child (CRC Committee) has recommended Sweden to take measures to ensure the rights of children with disabilities to be heard and to receive appropriate communication support in any decision-making that affects them.

Children's rights need to be ensured in relation to particular living arrangements

34. In October 2022, 318 girls and 531 boys lived in group homes for children with disabilities, granted according to the Act on Support and Service for Persons with Certain Functional Impairments (LSS). The share of children in this type of accommodation is decreasing, however with a slower pace in recent years.
35. An in-depth analysis in 2020 showed that the reasons for accommodation of children in group homes often relates to extensive nursing or medical needs. In some cases, the child has been refused personal assistance or had such assistance revoked. In 2023, the National Board of Health and Welfare stated that there have been signs of an increasingly difficult situation for families with children with disabilities. This development was deemed to indicate that the needs for support among children and their families are not always met. At the same time, there are indications that the application of recent legislative changes

to the so-called parental deduction has made it more difficult for some children to obtain personal assistance. The child's human rights impose an obligation on the State to act to enable children with disabilities to live at home regardless of extensive needs for support and supervision. More knowledge is needed about the extent to which accommodation in group homes for children could have been avoided through enhanced support to the child and the child's guardians. More knowledge is also needed about children's involvement in these decisions.

36. It is important that the handling of matters regarding housing with particular services for children with disabilities is based on a holistic view of the child's needs and situation, and on knowledge of child development and rights. In many municipalities less than 50 percent of case managers have a degree in social work. The knowledge requirements for LSS case managers need to be clarified, especially in matters relating to children.
37. There are examples where children have died or been seriously injured while in short-term stay facilities due to deficiencies in the service. These facilities are currently not subject to the same annual inspection requirements as group homes for children.

More attention needs to be paid to the situation of young persons with disabilities

38. Young persons with disabilities are more affected by mental illness than others and more often have stress-related symptoms. Efforts to prevent mental illness need to be strengthened. Among factors that promote mental health, young persons with disabilities highlight being able to do things themselves, getting necessary support and adaptations, having role models and a community, and having routines, regularity and adapted requirement levels. Self-reported mental health is better among school children who are physically active. However, fewer young persons with disabilities are satisfied with their leisure time. This group also describes obstacles to developing independence, including gradually gaining independence from their parents, preparing for adulthood and active participation in society. There is also a link between mental illness among young persons with disabilities and inadequate adaptation of the school environment.
39. Young persons with disabilities generally have less knowledge about sexual and reproductive health and rights than others. Youth counselling centres do not fully reach young persons with disabilities.
40. It is important to pay particular attention to the risk of children and young persons with disabilities becoming involved in crime and to take steps to prevent this from happening. In recent years Sweden has seen an increase in the proportion of young persons involved in serious crime. Young persons with neuropsychiatric disorders or intellectual disabilities are at higher risk. In 2023, the CRC Committee expressed deep concern and made recommendations to Sweden regarding the increasing involvement of children in organised crime as well as planned and implemented criminal law and policy measures in this area.

Recommendations

41. Act to strengthen the participation of children with disabilities in decisions, follow-up and implementation of interventions, including decisions on interventions in the form of housing in group homes.
42. Systematically monitor the development of the intervention housing with particular services for children or young persons under LSS, particularly with regard to the grounds on which the intervention is applied for.
43. Take action to ensure that young persons with disabilities receive sufficient support to have equal opportunities to develop their independence, prepare for adulthood and participate in the community.
44. Act to increase knowledge about the risk and extent of the involvement of children and young persons with disabilities in crime. Measures should seek to ensure effective and rights-based prevention and support. Any obstacles for children and young persons with disabilities to access crime preventive and outreach services need to be removed.

Article 8

Awareness-raising

Persons with disabilities need better knowledge of their rights

45. In a survey of persons with disabilities, conducted on behalf of the Institute, 35 percent of the respondents reported that they were unaware of the existence of the CRPD. 59 percent replied that they were aware of the CRPD, out of which 60 percent know what the Convention entails, while 29 percent said that they do not know. Respondents were also asked how easy or hard it is to find information on human rights. 32 percent said that it is rather difficult to find information on human rights and only 6 percent said that it is very easy.

Need to combat stereotypical notions of sexuality and parenthood

46. Persons with disabilities describe experiences of infantilisation and desexualisation by their surroundings. Many, in particular persons with intellectual disabilities, feel that they are not allowed to decide for themselves whether to become parents or not and that others

expect them to refrain from parenthood because of their disability. There are descriptions of feeling questioned as a parent and of being disadvantaged, discriminated and harassed.

Recommendations

47. Establish a long-term strategy to raise awareness among the population, including persons with disabilities themselves, about different disabilities and about the rights of persons with disabilities.
48. Act to combat stereotypical notions about persons with disabilities linked to sexuality, family formation and parenthood.

Article 9

Accessibility

Insufficient use of universal design

49. Universal design is a key principle in disability policy. Despite this, the MFD follow-up of the strategy for systematic monitoring of disability policy shows that universal design is not used by actors at the heart of the implementation of disability policy, in the context of their external mandates.

Shortcomings in work to remove barriers

50. At present, there are significant differences at local and regional level concerning how work with accessibility is conducted. A uniform and systematic approach is lacking. Research shows that accessibility work in municipalities often encounters resistance and that competing interests are prioritised, such as design preferences. Municipalities and regions often fail to include accessibility requirements in relevant procurements, despite binding regulation. Progress on “easily eliminated obstacles” is below expectations. Persons with disabilities are asking for easy ways to report barriers to accessibility.
51. In a survey carried out by the Institute, many of the responses concerned barriers to independently navigating public spaces, as well as the lack of availability of accessible housing. Civil society has emphasised the gradual phasing out of clear regulation for accessible and usable physical environment. If it is left to actors in the construction sector to identify solutions themselves, there is a clear risk of a reduction in the accessibility and

usability of new buildings, especially when supervision does not appear to be a priority in the municipalities.

Digitalisation is not equally accessible to everyone

52. A survey conducted by the Institute highlighted digitalisation as a main source of concern for persons with disabilities and as a major and serious barrier to participation. The issue has been repeatedly raised in meetings with civil society.
53. A large number of persons in Sweden, many of whom have disabilities, do not yet have access to electronic identification, which causes problems accessing banking services, shopping online or contacting authorities. The transition from manual to digital payment services especially affects persons with disabilities. Other challenges are filling in applications and forms digitally, reading small or hard-to-access text and managing the effect of website algorithms. Increased digitalisation also affect access to healthcare. The Swedish Agency for Digital Government works too little with the promotion of digital accessibility.

Recommendations

54. Create conditions for universal design to be used to a greater extent as an evaluation criterion in procurement contexts.
55. Establish a coherent monitoring system that measures the progression of accessibility based on indicators that measure the structure, process and performance of national, regional and municipal authorities.
56. Involve persons with disabilities, including children and young persons, in all work on digitalisation to create the conditions for persons with disabilities to benefit from digital development to the same extent as others.

Article 11

Situations of risk and humanitarian emergencies

Shortcomings in readiness to ensure rights in the event of crisis and emergencies

57. Actions during the COVID-19 pandemic revealed shortcomings in the preparedness to fulfil the CRPD rights in a situation of crisis. Inadequate efforts were made to ensure the right to freedom, self-determination, healthcare, education and work. Decisions during the pandemic affected elderly persons with disabilities in a discriminatory way.
58. The situation during COVID-19 revealed that key actors were not sufficiently prepared to reach out to everyone with accessible information. Persons with disabilities stress the need to strengthen access to crisis information in an easy-to-read format and to ensure continuous updates of the material.
59. Civil society actors testify to insufficient measures to ensure the rights of persons with disabilities in the reception of refugees from Ukraine. There have been deficiencies in accessible communication, accessible housing, adequate livelihoods, assistive devices and support for entering the labour market.
60. Many civil defence shelters are not designed to meet the needs of persons with disabilities. The Swedish Civil Contingencies Agency lacks information on accessibility in civil defence shelters.
61. The share of municipalities with continuity plans, evacuation plans and contingency plans has increased in recent years, but the increase now seems to have slowed down. There is still a high proportion of municipalities that lack plans for facilities for persons with disabilities. Many municipalities lack procedures to include emergency preparedness in procurement for interventions in the form of housing or home support.

Recommendations

62. Ensure that policy makers include a disability rights perspective in the development of strategies, action plans and proposals, as well as emergency preparedness evaluations.

Article 12

Equal recognition before the law

The transition from substitute decision-making to supported decision-making is too slow

63. There is a lack of legal means for people who have been provided with an administrator or trustee to demand participation and insight into many matters. There is a lack of legal clarity regarding the standing of the individual's own will. In the event of barriers to communication between the person represented and the person who represents you, there are no formal requirements to bridge these barriers. Administrators and trustees do not always receive sufficient support. There are well-documented deficiencies in the follow-up system.
64. Only the court can make the decision to end a guardianship. Persons with disabilities testify to years of struggle to free themselves from their administrator, often without success.
65. Many municipalities apply a model of supported decision making (Swedish: personligt ombud), which has positive effects on the individual's independence and participation in society. This service remains optional and assessments of who belongs to the target group vary. It is not possible to appeal a denial of the service.

Recommendations

66. Increase efforts to develop supported decision-making systems and phase out substitute decision-making including administrators.
67. Act to increase transparency and access to justice for persons wishing to report abuses of administrators or trustees and/or free themselves of the arrangement.

Article 13

Access to justice

Deficiencies in accessibility and knowledge prevent effective access to justice

68. Information given to individuals about decisions in legal proceedings is not always accessible. There are examples where persons with disabilities have not received the support necessary to understand accusations made against them. According to a decision by the Chancellor of Justice, it is the responsibility of defence lawyers to convey any needs that the individual has to the law enforcement authorities. The judiciary and legal representatives need more knowledge about different disabilities and how the justice system should act in order to make legal processes accessible.
69. Research shows that statements in courts, primarily from persons with neuropsychiatric disabilities, are at risk of being met with reluctance and hesitation if the diagnosis is known to the decision-maker. Even though the proportion of crimes against this group is high, few cases go to court. Among the cases leading to trial, there is a tendency to acquit offenders in cases where the offence was committed against a child with disabilities.

Deficiencies in accountability

70. There are currently no legal means to claim assistive devices, interpretation services, rehabilitation, healthcare and discrimination within the police and the judiciary. It is unclear which national legal remedies need to be exhausted before a complaint can be submitted to the CRPD Committee under Additional Protocol No. 2. Contrary to what has been done with regard to the Convention on the Rights of the Child, the Government has not conducted a comprehensive review of the enforceability of rights under the CRPD.
71. The courts are generally prevented from deciding on the merits of a case when a respondent concedes to pay a claim but denies liability for discrimination. Some case law challenges this, but the situation hampers redress and the development of precedents.

Limited possibilities to receive help to pursue legal action

72. In many court cases, there is no right to publicly funded legal counsel, even in complex legal issues that put high demands on the individual in terms of evidence and argumentation. The respondent may have a significant advantage in terms of resources, e.g. a public authority. This applies in cases which are clearly linked to disability rights and which

persons without disabilities typically do not litigate, such as disability support, transport services, legal capacity and supported decision-making.

Recommendations

73. Act to ensure that disability-related needs are identified at an early stage and met by police, prosecutors and other actors in the judicial system, including in preliminary investigations and trials.
74. Ensure enforceability of rights by reviewing existing remedies and removing practical and financial barriers for individuals to litigate arguable claims of violations of rights.

Articles 14–15

Liberty and security of the person, Freedom from torture or cruel, inhuman or degrading treatment or punishment

Widespread use of compulsory psychiatric care and shortcomings in preventive work

75. In 2022 approximately 12,600 persons were treated in institutional compulsory psychiatric care, including children.
76. Part of the assessment of the need for care is to consider whether the person in question is a danger to someone else. Thus, there is a preventive dimension to compulsory psychiatric care which otherwise does not apply to the deprivation of liberty of individuals. The regulations and the application of law also accept the use of compulsion against certain groups in a way that is not permitted in relation to others. An example of this is the approach in relation to disability due to schizophrenia compared to that of dementia.
77. There are considerable variations across the country regarding the likelihood of being subjected to compulsory psychiatric care. There are differences in the preventive efforts and in the perception of the use of compulsion. There are also shortcomings in the availability of voluntary psychiatric care and deficiencies in psychosocial interventions for persons with schizophrenia or schizophrenia-like conditions.

Use of coercive measures and a lack of self-determination in compulsory psychiatric care

78. In compulsory psychiatric care coercive measures such as seclusion (Swedish: avskiljning), restraint and non-consensual treatment, including electro-convulsive therapy (ECT), are still permitted. It is also permitted for children. Women appear to be more frequently subjected to coercive measures than men.
79. No steps have been taken to abolish the use of coercive measures. As to non-consensual treatment, the legal basis is partly unclear. A recent review has shown that, in compulsory psychiatric care of children, coercive measures are used without legal basis and that there are shortcomings in competence, self-inspection and the use of a children's rights perspective.
80. There is a general need for improvement in efforts to prevent the use of coercive measures. Neither the general law on patient participation nor the amendment for increased participation in compulsory psychiatric care has been fully implemented in compulsory psychiatric care and forensic psychiatric care. Indirect coercion occurs. Studies and evidence suggest that disabilities and other individual needs are not taken into account.
81. In 2023, the CRC Committee recommended Sweden to ban the use of isolation, solitary confinement and restraint of children in alternative care settings. In 2021, the European Committee for the Prevention of Torture (CPT) encouraged Sweden to take immediate steps to ensure that free and informed written consent is always obtained before ECT.
82. In 2023, a government inquiry presented a proposal which would allow the coercive measures currently permitted in compulsory psychiatric care to be used for persons treated for harmful substance abuse or addiction. There is a risk that such a change would negatively affect persons with neuropsychiatric or psychosocial disabilities.

Deficient rule of law and lack of control in compulsory psychiatric care and forensic psychiatric care

83. It is not possible to appeal several of the coercive measures used in psychiatric and forensic psychiatric care. There are also certain restrictions to obtaining a state financed legal representative. Persons with experience from compulsory care also testify to the fact that the legal assistance provided in certain proceedings does not ensure legal certainty due to insufficient economic compensation to legal counsels. In addition, expert doctors appointed by the court do not always meet with the patient before the court makes its decision.
84. A 2022 study indicates that there is a need to strengthen the information to patients on fundamental rights, on how to appeal deprivation-of-liberty decisions and on the right to legal representation.

85. The supervision carried out by the Health and Social Care Inspectorate (IVO) is inadequate. In addition, the current regulation does not guarantee regular inspection visits to psychiatric care units where children are subjected to compulsory care. A submitted proposal for a special body for development and regular inspection of psychiatric units where children are held in compulsory care was not adopted.
86. It is common for persons to continue to be detained in in-patient forensic psychiatric care even after being assessed to be ready to move to out-patient care. In 2022, in the part of the country where this group was largest, they made up 23.1 percent of those admitted. Lack of access to suitable accommodation in the municipality is reported to be the main obstacle to the transfer or discharge of patients. The law intended to regulate collaboration at discharge from inpatient care has had limited effect in the field of forensic psychiatry. The current situation was also pointed out by the CPT in 2021.

Coercive measures and violence in special residential homes

87. Seclusion (Swedish: avskiljning) and separate care (Swedish: vård i enskildhet) are permitted at special residential homes (SiS), where children with neuropsychiatric disabilities are over-represented. In addition, the care at SiS is mainly carried out in a way that constitutes deprivation of liberty. There is no minimum age limit for when treatment at SiS or coercive measures can be applied.
88. Individuals with neuropsychiatric disabilities are more often subjected to coercive measures than others. Girls, especially young girls, are more often subject to seclusion, while separate care is more often used for boys.
89. In 2023, the CRC Committee recommended that Sweden prohibit the use of isolation and seclusion for children. However, no action has yet been taken. The maximum time for seclusion at SiS was shortened through a legal amendment in 2018, but there is still no maximum time limit for separate care.
90. Reviews show that SiS has serious shortcomings in how coercive measures are used and the effectiveness of preventive efforts. Furthermore, there are indications that children and young persons with neuropsychiatric disabilities sometimes remain in SiS longer than necessary because the municipalities fail to organise appropriate support measures. Studies also repeatedly show that children are subjected to serious violations, degrading treatment, sexual abuse and the systematic use of force by staff in SiS.
91. The conflict management programme that the Government highlighted in its report to the Committee in 2019, No Power No Lose (NPNL), has received widespread criticism. Elements of the method have been equated with violence and the method has been assessed to involve extensive risk of injury, including painful grips and grips that should be exclusively used by the police.

92. There are barriers for children and young persons to effectively appeal decisions and report violations that occur in SiS. This applies, for example, to a lack of information given to the children, a lack of clarity regarding the possibility for younger children to appeal decisions themselves, limited possibilities for children over 15 years to obtain legal assistance, and insufficient possibilities to receive an independent assessment of reported abuses. A 2021 survey shows that the Victims' Rights Directive catalogue has not been fully implemented nor had an impact in practice in terms of victims deprived of liberty, including those living in SiS.

Restrictions, coercion and violence in housing for persons with disabilities

93. Reviews show that coercion, restrictive measures and violence commonly occur in group homes for adults and children with disabilities in Sweden. Among other things, reviews show that residents are locked up, restrained, held down, handcuffed or prevented from leaving their apartments. Residents have also been given drugs without their knowledge or consent.
94. Between 2016 and 2023 IVO revealed a number of cases involving children and young persons with disabilities, where cage-like beds and spaces were used in publicly operated facilities or with the knowledge or support of the public healthcare services. These include cage-like sleeping areas with bars and plexiglass from floor to ceiling and air-holes at ceiling height, as well as locking devices that made it possible to lock the person up. The phenomenon was found in municipalities and regions in different parts of the country.
95. It has been reported that persons living in group homes are monitored in their apartments without their knowledge or without knowing that they have the option to refuse. Civil society stakeholders note that there is a general trend towards increased use of various monitoring solutions.
96. Weaknesses in terms of insufficient competence and absent leadership contribute to the occurrence of coercion and restrictions in housing for persons with disabilities. Statistics also show that there are widespread problems with dysfunctional working cultures in these settings, which risk contributing to and maintaining the use of unauthorised and inappropriate working methods.
97. There is no binding and clear regulation regarding required knowledge and skills of managers and staff, or how many facilities one person can simultaneously be the manager of. Furthermore, there is no designated actor with a clear responsibility and dedicated resources to actively work with the dissemination and implementation of knowledge to relevant stakeholders.

Recommendations

98. Prohibit the use of coercive measures in the form of isolation and restraint of children.
99. Initiate a review of the regulatory framework of compulsory psychiatric care and forensic psychiatric care and their compliance with the CRPD.
100. Ensure that ECT is not used without free and informed consent.
101. Act to ensure effective and systematic prevention efforts regarding coercion and violence in compulsory psychiatric care, forensic psychiatric care and compulsory social care. Measures should include systematically gathering the experiences of persons with disabilities about compulsory care, coercive measures and support after discharge.
102. Act to identify and address structural deficiencies that lead to the use of violence, coercion and restrictions in group homes for persons with disabilities.

Article 16

Freedom from exploitation, violence and abuse

More knowledge is needed about exposure and available support to victims of violence

103. Statistical studies show a clear link between disability and increased exposure to violence. This involves all forms of violence, both in childhood and in adulthood, and regardless of gender identity, although the increased risk is relatively higher for women than for men. Among other things, studies show that persons with disabilities are at a greater risk than others of being exposed to various forms of sexual violence, such as abuse, threats, harassment and exploitation. More knowledge and reliable statistics on violence against persons with disabilities are needed.
104. Studies suggest that there are deficiencies in support for victims of violence, which can be expected to affect persons with disabilities in particular, based on their higher risk. Deficiencies relate to personal treatment, information, participation and the design and coordination of interventions. Studies also show that various forms of exposure to violence can be more difficult to detect when it concerns persons with disabilities due to prejudice and because persons with disabilities are not always considered in the templates used to identify victims of violence.

Insufficient measures to reduce bullying and abuse in schools and online

105. Bullying, violations and harassment include physical, psychological and sexual violence. For children and young persons, exposure often includes the school environment as well as the digital arena. Studies indicate that children and young persons with disabilities are exposed to a much greater extent than others.
106. Studies show a negative trend in bullying and abuse in recent years. Reviews point to shortcomings in how schools work against abuse and bullying and that the Internet more clearly needs to be included as a part of the schools' promotion and prevention efforts. There is a lack of clear and binding guidelines for the work of schools in this regard.

Recommendations

107. Ensure that measures to comply with the rights of persons with disabilities are included in all strategies, action plans, programmes and other initiatives aimed at prevention, detection, protection, support and rectification related to exposure to violence and abuse.
108. Ensure structured initiatives to prevent and detect bullying and abuse of children and young persons with disabilities at school and online, by for example initiating the development of a national action plan.
109. Act to ensure regular and representative gathering of knowledge about various forms of violence against persons with disabilities.

Article 19

Living independently and being included in the community

A negative trend and risk of further deterioration of rights

110. The number of persons with personal assistance decreased annually between 2015–2022. Access to certain other services such as companions and contact persons is also decreasing. On the other hand, the intervention of housing with particular services for adults according to LSS has increased significantly over a long period of time. The Swedish

National Board of Health and Welfare states that it cannot be ruled out that reduced personal support is a contributing factor to this development. The Institute has received information that municipalities sometimes guide individuals to apply for housing with particular services rather than offering individualised support and regular housing. Despite recent changes, the requirements to be granted personal assistance are still high and the difference in outcomes is smaller than expected.

111. There are indications that the respect for individual needs, interests and right to self-determination is decreasing. The Swedish National Board of Health and Welfare states that stakeholders' descriptions of requirements of medical certificates and to complete questionnaires about physical abilities, indicate that a medicalised approach has gained a foothold among case officers and decision-makers in municipalities.
112. Persons with disabilities describe that applications for personal support lead to far-reaching breaches of privacy. They also describe feelings of being distrusted, placed under suspicion and treated as a burden rather than as members of society and holders of rights. Currently, the political and media focus is on crimes within the welfare system rather than rights of those using the system.

Rights are not respected in housing with particular services for persons with disabilities

113. As described under Articles 14 and 15, serious abuses, including coercive and restrictive measures, occur in group homes for persons with disabilities. In addition, many people living in housing with particular services testify to a lack of self-determination and control, restricted ability to choose activities freely, a lack of influence over who provides the support and a lack of control over where they live and with whom. Disability rights organisations note deterioration in this respect in recent years.
114. It is perceived by stakeholders in civil society that co-location of different facilities for persons with disabilities is becoming more common. Some also sense a tendency towards increased size of group homes. There is a lack of official data on these matters. Currently, there is no binding and unambiguous regulation regarding the number of people that can reside in a group home at the same time, or regarding what is required in terms of settings to avoid an institutional living environment. No review of the system for support and service in housing with particular services has been carried out since the ratification of the CRPD. There is no process or action plan for deinstitutionalisation and transition to integrated systems that fulfil the needs and respect the rights of persons with disabilities.
115. The content or quality of the support received by an individual in housing with particular services cannot generally be appealed. According to the existing regulatory framework, operators of such facilities can largely decide for themselves how to handle feedback and complaints from individuals. As a result, the way complaints are handled differs and there is no guarantee that complaints are assessed by others than the facility itself. IVO has

no obligation to investigate individual complaints concerning interventions under LSS. Independent inspection is therefore not ensured.

Unequal access to disability support

116. Many municipalities develop their own guidelines to support the processing of applications for disability support. The guidelines may relate to which disabilities entitle a person to a particular intervention, the situations in which an intervention can be approved, or to what extent support can be given. Consequently, access to support, such as LSS housing, accompanying persons or personal assistance, varies between municipalities. The risk of losing vital support in case of a move to a different municipality can lead to lock-in effects and a limitation in the freedom to choose a place of living.
117. The responsibility for personal assistance is shared between the municipalities and the state. The shared responsibility creates a risk of inequality and legal uncertainty. There is also a risk that decisions about personal assistance will be based on financial considerations rather than on individual needs. In 2023, a government inquiry proposed placing responsibility for all personal assistance under the state. The Government has yet to announce how it intends to proceed with the proposal.

The level of assistance compensation is not keeping up with wage and cost trends

118. The level of state assistance compensation is not indexed and assistance users and employers testify that it is insufficient to guarantee rights compliance. The level of compensation creates difficulties in recruiting and retaining assistants and ensuring guidance and training for the quality of the intervention. According to civil society stakeholders, the allocation in the state budget for 2024 is insufficient and continues to lag behind overall wage and cost increases.

Some groups have less support despite belonging to the target group of the Convention

119. Access to guide services has decreased for persons with visual impairment, hearing loss or deaf-blindness. They are often referred to support provided through the Social Services Act, which lacks a clear disability rights perspective and has a lower level of ambition compared to LSS regarding the quality of life to be achieved through the interventions. Many persons with mental disabilities are also referred to interventions via the Social Services Act. It has become more difficult to be granted transport services, including for persons with visual impairment.

120. There are examples of persons who communicate by tactile sign language being denied support from persons who have knowledge of this means of communication.
121. The level of support for older persons varies depending on when and how the need for support arises. Those over 66 years cannot apply for personal assistance or for an increase in hours under LSS. Older persons are generally referred to interventions provided through the Social Services Act, such as home care or special housing. It can be questioned whether these systems meet the CRPD requirements regarding self-determination and inclusion in the community.

Recommendations

122. Establish a deinstitutionalisation strategy, including a transition to support for living conditions characterised by self-determination and community inclusion on equal basis with others. This work must include measures to strengthen the right to personal assistance so that more persons with disabilities can live independently and be included in the community, without being referred to housing with particular services.
123. Ensure access to accompanying services for persons with visual impairment and deaf-blindness so they can participate in the community, have control over their choices on equal basis with others and not become socially isolated.
124. Act to ensure the right to support for self-determination and community inclusion for older persons with impairments regardless of at what age they appear.

Article 21

Freedom of expression and opinion, and access to information

Negative developments in access to interpreters

125. Extensive structural problems are preventing adequate access to sign language and deaf-blind and writing interpretation. The regulatory framework is difficult to understand, responsibility is divided, the understanding of the concept of everyday interpretation is all but uniform, and access to interpreting services for leisure activities and participation in civil society is limited. Other aspects raised by persons with disabilities are that access to interpretation is overly linked to diagnosis rather than need and that the current systems

for booking interpretation do not facilitate the use of the service. In many parts of the country, the interpretation service is underfunded, leading to a general restrictiveness in the granting of the service. The individual cannot appeal a decision to deny an application for interpretation services. There are worrying indications that access to trained sign language, deaf-blind and writing interpreters is decreasing.

126. The lack of access to interpretation service is the same as ten years ago. Studies indicate that there is a negative development in the conditions for the interpretation services and the possibilities for individuals to get interpretation.
127. In this report, access to interpretation service and the possibility of using sign language to communicate has been linked to Article 21(e). However, on the basis of the problems that characterise the issue in Sweden, the question is also clearly linked to Articles 5, 9, 19, 24, 27 and 30 of the Convention.

Recommendations

128. Act to provide an equitable, qualitative and easily accessible interpretation service for persons with disabilities that satisfies the right to language, self-determination and participation in the community.
129. Act to ensure long-term access to educational sign language, deaf-blind and writing interpreters.

Article 23

Respect for home and the family

Unequal conditions for parenthood

130. Parents with disabilities describe that providers of support do not sufficiently consider a holistic and family perspective. Parents describe a lack of inclusion within child health centres, preschools and schools, as well as a lack of information and assistive devices. This lack of support has negative consequences for the children in the family.

Barriers to family reunification of persons with disabilities

131. The right to family reunification for refugees and persons with subsidiary protection status has, since 2016, been conditional on detailed income and housing requirements. This arrangement is particularly hard on persons who find it difficult to establish themselves in the open labour market, including women with a migration background and disabilities.

Recommendations

132. Analyse the existing availability of support to parents with disabilities, including any barriers faced by the group and the extent to which needs are met through the support systems currently in place.
133. Review the rules on family reunification to ensure that persons with disabilities are not particularly disadvantaged by the maintenance requirement.

Article 24

Education

The education system is not sufficiently inclusive

134. Children are divided into different school forms, some of which target children with certain disabilities. The use of segregating measures has increased. The Government has further facilitated special solutions, especially in the form of segregated teaching-groups and emergency schools.
135. Education in schools for children with intellectual disabilities (adapted schools), has been criticised for not sufficiently focusing on knowledge development and many teachers lack teaching qualifications. Generally, placement in adapted schools is voluntary and preceded by an assessment. The placement can have major consequences for the individual as the student risks getting stuck in segregating structures. Choice is severely restricted for these children as adapted upper secondary school is the only way forward, after which there is no eligibility for higher education. 2020, more than half had moved directly to daily activities according to LSS in the autumn after completed studies.

Lack of accessibility in primary education

136. Research shows that there are many children in primary school who lack the capacity to meet the requirements of the curricula and fail to obtain a passing grade, even if they receive support. Children with weak theoretical capacity are particularly affected. Non completion of primary education significantly influences the long-term socio-economic situation of the individual and is one of the strongest risk factors for psychosocial problems.
137. Surveys made by the Swedish Schools Inspectorate show that the educational, social and physical learning environment needs to be more accessible in many schools. According to a school survey from 2023, 60 percent of pupils with neuropsychiatric disabilities experience difficulties keeping up with school requirements and 49 percent receive little or no support and adjustments. Pupils with neuropsychiatric disabilities and ethnic backgrounds other than Swedish, appear to be particularly vulnerable to discrimination in a school context and experience greater difficulties in accessing support. Studies show that half of students with autism fail to complete primary education. Many children develop a pattern of absenteeism, for which neuropsychiatric disabilities are a risk factor. This trend seems to be negative over time, and according to an interview study with affected children, this development links to a lack of dedicated support, to a difficult school environment, to mental health related issues, to a lack of adult relationships and to a challenging transition between grade levels.
138. There are indications that schools in Sweden are cutting back on special education teachers, student assistants and other staff who have a central role in removing barriers and increasing accessibility for pupils with disabilities.
139. It is important to expand solutions that break segregating patterns and increase the participation in society of persons with disabilities. One good example is folk highschoools, a form of education that works well for persons with disabilities. This type of school increases the possibility of completing upper secondary school studies for certain groups of young persons who are outside the labour market.

No free choice of schools for children with disabilities

140. In 2014, the CRPD Committee noted that the free choice of schools is effectively non-existent for pupils with disabilities. The State has not implemented sufficient measures to improve this situation.

Recommendations

141. Carry out a review of how the right to education is met for children with disabilities in adapted schools, special needs schools and primary schools.

142. Act to ensure that the right of the pupil to adequate, personalised support measures and reasonable accommodation is met.
143. Strengthen access to higher education and vocational training for persons with disabilities.

Articles 25–26

Health, habilitation and rehabilitation

Inequality in health and a lack of access to care and assistive technology

144. Persons with disabilities have poorer physical and mental health than the rest of the population. Among other things, persons with intellectual disabilities have higher morbidity and lower life expectancy. Persons with disabilities who live in particular living arrangements or have housing support are groups with significantly poorer health than others. The average life expectancy for persons with schizophrenia is about 15 years shorter than for the general population.
145. Many persons with disability face barriers accessing healthcare services due to limited possibilities to use digital communication channels or due to inaccessible information. Persons with disabilities testify to the lack of equipment for examination and treatment of non-normative bodies. There are also differences in the healthcare provided.
146. There are restrictions on access to healthcare for persons living in special forms of housing under LSS or housing for elderly persons with extensive support needs. These include limited access to doctors, digital barriers and barriers due to lack of knowledge, skills and means of communication.
147. Persons with disabilities from the Sami community describe that they encounter low levels of knowledge about Sami society and that municipal and regional interventions are poorly adapted to their situation. These deficiencies have led to misunderstandings and missed or inadequate interventions.
148. About half of all those seeking care for gender dysphoria also have a neuropsychiatric and/or mental disability. There are no clinical guidelines for the care of this group. There are also indications of a lack of transgender and autism competence in healthcare and that barriers arise due to the combination of transgender identity and autism.

149. Access to assistive devices or habilitation measures vary across the country. Fees for assistive devices differ and persons with disabilities describe that costs sometimes constitute a barrier to obtaining the aids at all. Access to habilitation and rehabilitation is sometimes limited by large geographical distances.

Weaknesses in psychiatric care strongly affect persons with disabilities

150. There are major shortcomings in the availability of voluntary psychiatric care and the wait for assessment and treatment is generally long. Waiting times and care content also differ substantially across the country. Representatives of persons with mental illness perceive that growing numbers of patients turn to privately run healthcare services. This could further increase the inequality in health for persons with disability.

151. Accessibility and quality of psychiatric care are affected by delimitation problems and a lack of coordination between different actors. Necessary interventions are not provided, are applied too late or become ineffective. There are descriptions of inadequate coordination and knowledge leading to persons with intellectual disabilities or autism being referred to psychiatric care rather than receiving other forms of support, with an increased risk of being subjected to coercive measures.

Need to strengthen patient involvement and participation

152. A number of reports indicate that the respect for patients' needs, preferences and prerequisites in healthcare services is unsatisfactory. Persons with disabilities testify to a gradual return to a medical approach to disability in which individual needs, preferences and self-determination are not respected.

Recommendations

153. Strengthen the requirements for systematic participation of persons with disabilities in the planning, design, monitoring and evaluation of accessibility, care processes and working methods in healthcare.

154. Act to improve access to health care for persons with disabilities who live in particular living arrangements or have other housing interventions.

155. Act to increase awareness of the obstacles persons with disabilities encounter in healthcare, including intersectional analysis on the basis of ethnicity, LGBTQI+, gender and age.

Article 27

Work and employment

Lower rate of employment, discrimination and unsatisfactory working conditions

156. Persons with disabilities face greater levels of unemployment than the general population. Fewer are in permanent employment and a lower percentage of those employed work full time. Persons with disabilities with reduced working capacity face a higher risk of long-term unemployment. Low levels of education, training that does not meet the employer's requirements, lack of knowledge of Swedish, various health problems or social problems, can each individually or in combination make it very difficult for job seekers with disabilities to establish themselves on the labour market on a permanent basis.
157. Experiences of discrimination that prevent entry into the labour market are common for persons with disabilities. Many young LGBTQI+ persons and persons with a foreign background experience that having disabilities reduces their opportunities in working life even further.
158. Persons with disabilities are on average less satisfied with their working environment than persons without disabilities. Many testify to bullying, offensive treatment and harassment by managers or co-workers.

Need for better support to enter the labour market and have a sustainable working life

159. The support for persons with disabilities to enter and remain in the labour market has deteriorated due to recent reforms in the Public Employment Service. This includes an increased use of digital solutions combined with reduced personal service. Interventions from the Public Employment Service such as grants for assistive devices, salary subsidies and interpreters have decreased. Persons with disabilities state that necessary support and assistive devices are often delayed, and that access to necessary expertise has decreased. The various types of support need to be given to a greater extent on the basis of individual prerequisites and needs. It is important that not only those closest to the labour market have access to supportive interventions. Support also needs to be strengthened for those in employment in order to enable a more sustainable working life.
160. Young persons with disabilities face particular challenges when entering the labour market. Both promotional and support measures need to be improved. Joint efforts on the part of schools, employers and the Public employment service have been shown to be important. Insufficient funding is given as a reason why interventions for this group are

inadequate. The legal responsibility of municipalities for the group is limited, especially for persons between 21 and 29 years.

Special arrangements for work and employment are flawed

161. Surveys show that the proportion of persons in daily activities according to LSS has increased significantly over time and that it cannot be ruled out that a reduction in labour market support is a contributing factor. One view expressed to the Institute is that young persons with disabilities often move from school to daily activities according to LSS, despite capacity to work in the regular labour market with adequate support. Transitions from daily activities according to LSS to the regular labour market seem to be uncommon. There is a risk that the intervention creates a lock-in effect.
162. A recent review of Samhall AB's operations shows, among other things, that working groups are too large to effectively support and promote the development of employees. Shortcomings are attributed to insufficient governance and an absence of stable funding.

Recommendations

163. Adopt an action plan to support the employment of persons with disabilities in the regular labour market, including by rapidly identifying and meeting needs for support and assistive devices.
164. Concretise the regulation and strengthen the supervision of systematic work environment management, aiming at prevention of discrimination on the basis of disability in working life.

Article 28

Adequate standard of living and social protection

Economic conditions are still worse for persons with disabilities

165. Persons with disabilities have lower disposable income than average and are more likely to have a low income standard. Persons with disabilities are more likely to find it difficult to make ends meet in their household finances and fewer perceive they can absorb unexpected expenses. They more often refrain from holiday travel and leisure activities due to financial constraints.

166. In 2022, social security expenditures compared to gross domestic product were at their lowest level in 40 years. Expenditures for sickness and disability benefits have decreased more than family and child benefits and other payments. Persons who are dependent on social security benefits have a poor income forecast from a life perspective. For persons receiving financial support from municipalities, the margin for consumption is becoming smaller compared to that of wage workers.
167. The compensation for additional costs for persons with disabilities can only be approved when one reaches a certain level of additional costs and not all costs can be reimbursed. Many applications are denied, including applications from parents of children with disabilities. A review shows that it is difficult for many applicants to understand the regulatory framework.

Barriers for those who are new in Sweden

168. The level of the daily allowance offered to some persons who are new in Sweden has not been adjusted since 1994. Accommodation offered to asylum seekers and newly arrived persons with a residence permit often lacks accessibility and is usually not permanent. Persons with disabilities who are new in Sweden encounter difficulties in employment and courses in Swedish for immigrants are not always accessible. Persons from this group also describe difficulties in navigating the support system and in knowing their rights.

Recommendations

169. Act to ensure that the levels of compensation in social security benefits and the rest of the financial safety net are sufficient to fulfil the right to an adequate standard of living for all persons with disabilities. Include measures to combat inequalities in the living conditions of persons with disabilities.
170. Ensure that the systems aimed at supporting and integrating persons who are new to Sweden fulfil the rights of persons with disabilities.

Article 29

Participation in political and public life

Insufficient accessibility prevents participation in democracy

171. Persons with disabilities have lower voter turnout than average. They are less satisfied with democracy and have less confidence in authorities and democratic elections.
172. Insufficient accessibility of polling stations, inadequate voter assistance and inadequate information created barriers in the 2022 elections. There is a need to strengthen the possibility for persons with visual impairment to vote while maintaining polling secrecy. There is a lack of independent supervision of the accessibility of municipal polling stations.

Recommendations

173. Strengthen opportunities for accountability when inadequate accessibility prevents persons with disabilities from participating in democracy on equal terms with others.

Article 31

Statistics and data collection

Need for improvement of data collection

174. Despite some positive changes, there are still several difficulties in defining and collecting data from persons with disabilities. Definitions that are expected to be overlapping do not always overlap. With the current survey questions, there is a risk that large groups of persons with disabilities are excluded. There are also indications that the response rate among persons with disabilities is lower than in the rest of the population.

Recommendations

175. Act to include questions about disability in more surveys at the national, regional and municipal level, in a systematic and coherent manner.

176. Ensure that persons with disabilities are included in surveys on equal terms and to the same extent as others, including children in adapted schools, persons living in particular living arrangements and elderly.

Article 33

National implementation and monitoring

Preconditions for the Institute to fulfil its role in the long-term need to be ensured

177. In April 2023, the Institute applied for membership in the Global Alliance for National Human Rights Institutions (GANHRI). The outlook is considered good, but not certain. Among other concerns, it is unclear whether the law fully fulfils the requirements of the Paris principles regarding the appointment, remuneration and dismissal criteria for board members. There are also concerns regarding a lack of protection for the Institute's independence and financial autonomy.

Recommendations

178. Act to ensure that the Institute is in a position to carry out its role as a national mechanism under Article 33(2), including compliance with the Paris principles.



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