Norges institusjon for menneskerettigheter

UN Committee on the Rights of Persons with Disabilities
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Supplementary information from the Norwegian National Human Rights Institution to the UN Committee on the Rights of Persons with Disabilities in relation to the hearing of the 1st periodic report of Norway on 25-26 March 2019

Reference is made to the Committee's invitation to provide country-specific information prior to the hearing of Norway's 1st periodic report at the Committee's 21st session.

The Norwegian National Human Rights Institution (hereinafter: NIM) was established 1 July 2015 as an independent institution under new legislation adopted by Parliament. NIM has a specific mandate to protect and promote international human rights in Norway, as well as to monitor how the authorities respect their international human rights obligations. Submitting supplementary reports to international human rights treaty monitoring bodies is an essential tool for an NHRI to fulfil its mandate.

In March 2017, we were granted A-status by GANHRI, thus recognising that NIM is fully compliant with the UN Paris Principles.

In relation to the Convention on the Rights of Persons with Disabilities (CRPD), it is notable that NIM has a statutory Advisory Council which meets quarterly to provide input and advise to our human rights work. The Council has fourteen members, including the Norwegian Federation of Organisations of Disabled People (FFO), an umbrella organisation with 82 member-organisations, and the Equality and Anti-Discrimination Ombudsman, which is specifically mandated to monitor implementation of CRPD.

This report has been prepared in consultation with the Equality and Anti-Discrimination Ombudsman, the Parliamentary Ombudsman and the Ombudsman for Children. The latter two have also provided written inputs on specific issues.

We hereby take the opportunity to draw your attention to seven issues which we suggest that the Committee address in its deliberations with and recommendations to Norway. Our submission does not reflect all relevant human rights challenges in Norway within the scope of the International Convention on the Rights of Persons with Disabilities.

Yours sincerely
On behalf of the Norwegian National Human Rights Institution

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Innhold

1. Discrimination and living conditions for Samí indigenous persons with disabilities, national minorities and other vulnerable groups

Reference is made to List of Issues paras. 2 (b), 19 (a), 20 (c) and (d), 22 (c), 23, and the corresponding state replies.

A government-sponsored study to provide research-based knowledge for the implementation of CRPD indicates that living conditions for all persons with intellectual disabilities living in Sámi areas were poorer than other comparable populations when it concerns housing, education, work, leisure, economy and health.[1] In some areas, there are substantial differences in living conditions for Sámi persons with intellectual disabilities compared to the living conditions for those with intellectual disabilities without Sámi background, especially when it concerns harassment and violence.[2]

Recommendations based on the study, include measures against harassment, preventive measures and treatment of mental health and to adapt suitable living and other services to Sámi persons with disabilities. One of the challenges seems to be that welfare institutions may have insufficient understanding of Sámi culture.[3]

To our knowledge there is no specific research on the living conditions for persons with disabilities belonging to national minorities, for example Roma and Tater/Romani. Researchers point out that there is a need for gathering more statistics and knowledge on the living conditions of persons with various kinds of disabilities, combined with factors such as gender, age and ethnicity.[4] We are also aware of the State Party's challenges in producing statistics on ethnic groups and the steps taken by the State Party towards generating more statistics.[5] However, taking into consideration other human rights challenges faced by minorities, and the lack of general statistics on the living conditions of persons belonging to national minorities, there is a need to ascertain whether persons with disabilities within these groups also face poorer living conditions than comparable groups without minority backgrounds.

Suggested recommendations:

- The State Party should take steps to strengthen protection of Sámi persons with disabilities.
- The State Party should investigate if persons with disabilities belonging to other minorities such as the national minorities Roma and Tater/Romani, also face poorer living conditions than comparable groups without minority backgrounds.

[1] Gjertsen, Fedreheim, Fylling, Kartlegging av levekårene til personer med utviklingshemming i samiske områder, Avdeling vernepleie, UIT, The Artic University of Norway, 2017, p. 8 ff.

[2] Ibid. p. 78, 89, 130.

[3] Ibid. p. 132 ff. cf. p. 134 f.

[4] See Hugaas Molden, Tøssebro, Wendelborg, Bruk av statistiske indikatorer i rapportering til CRPD, NTNU Samfunnsforskning Trondheim 2016, p. 69.

[5] See Norway's reply to List of Issues question 22 c, page 19, CRPD/C/NOR/Q/1/Add.1.

2. The Act on Guardianship in practice

Reference is made to the State Report paras. 75-93 and List of Issues paras. 1 (a) and 9 with the corresponding state replies.

The question at present is whether the Guardianship Act, as it is practiced, is in compliance with CRPD. Norway made a declaration when ratifying the CRPD stating its understanding that that Article 12 allows substituted decision-making only "when necessary, as a last resort and subject to safeguards".

The purpose of the Guardianship Act is to ensure that persons who need help and have a recognized diagnosis, for example different intellectual impairments or dementia, have their interests taken care of by an appointed guardian. The person under guardianship must agree to the guardianship, its scope and to the actual guardian. In specific situations, however, the law entails that self-determination does not need to be respected if the person does not understand the issue at hand (lacks decision making competence). Based on medical opinion, the county governor decides whether a person has decision making competence. According to the law, guardianships may also include full or partial restriction on legal capacity; such a decision is to be made by a court and does not require the consent of the person under guardianship. The County Governor is the local authority for guardianship matters.[6]

In 2018, the Legal Department of the Ministry of Justice and Public Security stated that the law must be interpreted to mean that a person can only be placed under guardianship against his or her will by deprivation of legal capacity established by a court.[7] This is so regardless of whether the person has decision-making competence or not. However, a broad assessment of the person's wishes is not required, and if there is nothing to suggest differently, there is a presumption for assuming that a guardianship is not contrary to the wishes and will of the person. This interpretation is now incorporated into a new proposal from the government, amending the Guardianship Act accordingly.[8] The government has, in a public hearing, explicitly asked stakeholders to voice an opinion on the issue of presumption.[9]

A PhD study evaluating the guardianship practice concerning persons with intellectual impairment in one county in Norway, found that in 165 out of 167 cases from 2015, the county governor found that the person had legal capacity. [10] However, in almost 50 per cent of the cases, persons with intellectual impairment were declared not competent to make decisions because of their disability status. The study concluded that the Norwegian

[6] Guardianship Act section 4.

[7] Legal Opinion issued by the Legal Department, JDLOV-2018-119.

[8] Høringsnotat, Snr. 18/5852, november 2018, Endringer i vergemålsloven mv.

[9] Høringsnotat, Snr. 18/5852, november 2018, Endringer i vergemålsloven mv., page 26.

[10] Skarstad, K., 2018. Ensuring human rights for persons with intellectual disabilities? *The International Journal of Human Rights*, 22(6), pp.774–800. Skarstad bases her conclusion on an analysis of all guardianship decisions (in total 167) made by the county governor in Oslo and Akershus in Norway in 2015 concerning adults with intellectual impairment. To ensure verifiability, the results were triangulated with interviews and other national sources.

system denies the self-determination of persons with intellectual impairment solely based on their disability status, and that denial seems to be a general rule and is not used as a last resort.

Studies indicate that in most cases, the mandates of guardians are broad and generic, and not adapted to the individual needs of the person under guardianship.[11] The mandates often concern both economic and personal matters. In many instances, the county governor does not map the needs of the person, or documentation is lacking on whether the person has been given the possibility to express her or his view.[12]

An additional issue is that many guardians have guardianship for too many persons. In 2017, 32 guardians had guardianship for more than 100 persons, and 325 guardians had 21-100 guardianships.[13] There is lack of knowledge about how guardians conduct their work in such circumstances. Furthermore, the county governors do not systematically carry out supervision of the guardians. The county governors also lack sufficient knowledge concerning the training of guardians, and most county governors ask for national guidelines on how to carry out supervision of the guardians, how to assess a person's competence to consent and how to ensure individual adaptation of guardianships.[14] The Parliament has decided that the recommendations from the Auditor General, including national guidelines must be followed up.

Suggested recommendations:

- The State Party should ensure that no persons are placed under guardianship against their will.
- The State Party should consider developing supported decision making with a view to minimizing substituted decision-making, and to consider changing the terminology in the law from *guardianship* to *supported decision making.*
- The State Party should in any event ensure that substituted decision making is used only as a last resort and that the mandates of guardians are based on specific needs and adapted to the individual persons under guardianship.
- The State Party should issue national guidelines on the assessment of competence to consent, individual adaptation of guardianships as well as on the supervision of guardians.
- The State Party should ensure that the capacity of guardians correspond to the number of guardianships that are placed under their care and provide further training.

[11] The Auditor General's report on the implementation of the new Guardianship Law. Dokument 3:6 (2017-2018), chapters 4.2.3 and 7.2; Skarstad (2018).

[12] (op cit) Dokument 3:6 (2017-2018), chapters 2.1, 4.2.2-4.2.3; Skarstad (2018).

[13] https://www.vergemal.no/getfile.php/4126567.2573.wwjpkmwtnsuiui/A%CC%8Arsmelding-vergema%CC%8Al-2017-oppslag.pdf, p. 30.

[14] (op cit) Dokument 3:6 (2017-2018), chapters 2.3-2.4, 4.6, 5.3.2, 7.3-7.4.

3. Use of coercion and persons with disabilities

3.1. Use of coercion in mental healthcare

Reference is made to the State Report paras. 115-118 and 128-129.

The Government's National Strategy for Increased Voluntariness in the Mental Health Services (2012-2015) did not lead to the desired reduction in the use of coercion.[15] Thus, in 2016 the Government adopted a number of amendments to the Mental Health Care Act and established a Commission for the review of legislation on the use of coercion ("Tvangslovutvalget" which will submit its report in June 2019).

Section 3-3 of the amended Act specifies that patients with the capacity to consent cannot be treated against their will, except in circumstances when they represent a serious risk to their own life or the health or life of others. The Act also strengthens procedural safeguards, such as extending the time for examination before using forced medication (5 days), free legal aid council (up to 5 hours) when challenging treatment without consent and obliging health professionals to consult with another qualified professional (but not requiring institutionally independent) prior to decision on non-consensual treatment.[16]

Reports on practice, as documented by the Parliamentary Ombudsman's National Preventive Mechanism (NPM) visiting twelve different institutions in 2015-2018,[17] has shown that coercion such as restraints, segregation and involuntary treatment is often applied excessively or for a prolonged time, without respecting legal safeguards. This emphasises the need to strengthen procedural safeguards for the patients, including more thorough written documentation of coercive treatment and focus on considering less intrusive measures before using force. The NPM in its reports voiced particular concern about the use of long-term segregation (shielding) of patients which often take place in prison-like premises, with very limited opportunity for meaningful human contact and purposeful activities. In two recent complaints,[18] the Ombudsman also found that the involuntary medication was not in accordance with the Mental Health Care Act which requires an individual assessment that there is "high probability" that the patient would benefit from a particular medication.

Furthermore, the use of coercive electroconvulsive treatment (ECT) in mental health care is of particular concern. There is no clear legal basis in formal law or regulation for the use of non-consensual ECT and the authorities have no complete factual overview on the use

[15] CCPR/C/NOR/7 para. 113, submitted in 2017.

[16] CCPR/C/NOR/7 para. 114.

[17] See the website of the NPM in English: https://www.sivilombudsmannen.no/en/visit-reports/.

[18] Tvangsmedisinering – særlig om kravet til «stor sannsynlighet» for positiv effekt, 18.12.2018 (2017/543) and Fylkesmannens vedtak om tvangsmedisinering – krav om «stor sannsynlighet» for vesentlig positiv effekt og enkelte andre vilkår, 21.1.2019 (2017/3156).

of coercive ECT.[19] It is expected that the ongoing legislative review on use of coercion in the health sector, including in mental health care, will address this and other issues. The report of this governmental commission is due in June 2019.

Suggested recommendations:

- The State Party should continue its efforts to end the unjustified use of coercive force, including through legislative measures.
- The State Party should ensure further reduction of the use of coercion, including through training of staff, prioritizing alternative and less intrusive methods, as well as strengthening procedural guarantees and control.

3.2. Mentally ill in prison – use of isolation

In 2016, the Directorate of Health and the Directorate of Norwegian Correctional Service published a joint report on the treatment of prisoners with mental illness and substance abuse problems ("Oppfølging av innsatte med psykiske lidelser og/eller rusmiddelproblemer"). The report highlights that due to insufficient staff and the demanding behavior of inmates, there is frequent use of isolated for extended periods of time. There is also concern that this group of inmates does not receive adequate mental healthcare. Reports from the Parliamentary ombudsman's NPM after visits to 20 prisons and an immigration detention centre in 2014-2018 has shown that highly vulnerable persons are subjected to solitary confinement, isolation and similar regimes without meaningful human contact, including inmates with serious mental health conditions or acute suicide risk.

Suggested recommendation:

- The State should take measures to ensure that inmates with symptoms of severe mental illness are properly diagnosed and treated, and that they are not subjected to isolation.

[19] Norwegian Directorate of Health, *"Nasjonal faglig retningslinje om bruk av elektrokonvulsiv behandling – ECT*" (National Guidelines on the Use of Electroconvulsive Treatment – ECT"), June 2017 and visits conducted by the NPM.

3.3. Use of coercion and persons with intellectual impairment

Reference is made to State Report paras. 110-114 and paras. 124-125, and to List of Issues paras. 3, 11 (b) and (d), 20 (c) and the corresponding state replies.

The Health and Care Services Act chapter 9 allows the use of coercion and force against persons with intellectual impairment to protect against serious harm to themselves or others and aims to prevent and limit the use of coercion. Coercion and force may be used as a) harm-reducing measures in emergency situations, b) as planned harm-reducing measures in repeated emergency situations, or c) as measures to satisfy the health care user or patient's fundamental needs for food and drink, clothing, rest, sleep, hygiene and personal safety, including training initiatives.[20]

Upon ratification of the CRPD, Norway declared its understanding that Articles 14 and 25 of the CRPD "allow for compulsory care or treatment of persons, including measures to treat mental illnesses, when circumstances render treatment of this kind necessary as a last resort, and the treatment is subject to legal safeguards". In 2016, a governmental commission concluded that the rules on use of coercion and force against persons with intellectual impairment under the Health and Care Services Act discriminate against persons with intellectual impairment because they apply only to persons with intellectual impairment.[21] The commission recommended replacing the rules with general rules, which do not require a diagnosis. Another governmental commission ("Tvangslovutvalget") is currently evaluating the rules on the use of coercion across the health sector. The commission's report is due by June 2019.

In practice, the level of use of coercion and force against persons with intellectual impairment is high and has increased. In 2017, 1503 decisions on planned use of coercion and force were approved.[22] The Norwegian Board of Health Supervision is concerned with the increase in use of coercion and force against persons with intellectual impairment.[23] Furthermore, decisions on the use of coercion and force seem to be rudimentary and to lack explicit considerations of the right of persons with intellectual impairment to self-determination. An examination of 121 coercive-care decisions from 2015 from the County Governor in Oslo and Akershus indicates that the right to self-determination of persons with intellectual impairment is insufficiently protected.[24]

[20] Health and Care Services Act section 9-5.

[21] Official Norwegian Report 2016: 17 *På lik linje*, chapters 12.7.1 and 19.

[22] https://www.helsetilsynet.no/globalassets/upload/publikasjoner/aarsrapporter/aarsrapport2017.pdf , p. 13.

[23] (ibid) p. 56.

[24] (op cit) Kjersti Skarstad (2018): Ensuring human rights for persons with intellectual disabilities?, The International Journal of Human Rights, DOI: 10.1080/13642987.2018.1454903.

An additional issue is that qualified personnel is lacking. In the majority of cases where coercion or force is used (3 of 4), the measures are carried out by unskilled personnel. Thus, dispensation from the right to qualified personnel when coercion or force is used as a planned measure, seems to be the general rule. In 2017, dispensation from the qualification requirement were applied for in 1175 cases. Dispensation was grated in 1093 cases.[25]

We note that the State Party has highlighted that the Directorate of Health is developing guidance material for health personnel working with people with intellectual disabilities, and that the annual state budget allocates resources for measures aimed at strengthening competence in health and care services for people with intellectual disabilities.[26]

Suggested recommendations:

- The State Party should reduce the use of coercion and force against persons with intellectual impairment and ensure that decisions on the use of coercion and force against these individuals are taken only by qualified health care personnel in accordance with stringent criteria, subject to adequate legal safeguards, and with due respect to the right to self-determination.
- The State Party should take steps to ensure that health care personnel in contact with persons with intellectual disabilities have adequate knowledge of human rights obligations and national legislation on the use of coercion and force, including detailed guidance material.

3.4. Use of coercion and older persons in nursing homes

Reference is made to the State Report paras. 126-127, and to List of Issues paras. 3, 11 (b), 11 (d), 20 (c) and the State's corresponding replies.

According to chapter 4 of the Patient's Rights Act, healthcare can only be given with the consent of the patient unless the use of coercion is justified on legal grounds. In 2009, the new provision 4A in the Act came into force. This provision specifies that involuntary healthcare can only be justified towards patients who lack decision competence and resist healthcare, in order to avoid serious harm to the patient. It should be noted that approximately 80% of 40,000 residents in nursing homes are diagnosed with dementia and encompassing disabilities.

[25] https://www.helsetilsynet.no/globalassets/upload/publikasjoner/aarsrapporter/aarsrapport2017.pdf p. 56 (table 17).

[26] Cf. Norway's replies to CRPD List of Issues, CRPD/C/NOR/Q/1/Add.1.

The Norwegian Board of Health conducted a systemic audit of practices in nursing homes in 103 municipalities in the period 2011-2012.[27] The audit revealed extensive use of coercion contrary to the provisions in Chapter 4A. It also found that the provisions, including guidelines on its implementation, were not well known to healthcare professionals, including the need to adopt a written decision when using coercive treatment. The report stated, among other things, that there is uncertainty among health care personnel on how to assess whether a patient has the capacity to consent, what constitutes a valid consent and that use of coercion and force are to be used only as a means of last resort.

A thematic report from the former National Institution in 2014 supported this finding and questioned whether the extensive use of forced measures against residents of Norwegian nursing homes was in line with our human rights obligations under Article 8 of the EHCR.[28] The report recommended, among other things, that the authorities undertake a detailed mapping of the problem in consultation with affected individuals. A recent study by Statistics Norway on behalf of NIM, further documented the lack of registration of the use of coercive healthcare.[29] Only half of the municipalities had in 2017 reported on instances of coercive healthcare in spite of the legal obligation to do so since 2009.

Suggested recommendations

- The State Party should take steps to reduce the use of coercion and force against older persons in residential care homes and ensure that decisions on the use of coercion and force against these individuals are taken only in accordance with stringent criteria, subject to adequate legal safeguards and with due respect to the right of self-determination.
- The State Party should ensure adequate documentation and reporting on the use of coercion and force in care homes.
- The State Party should take steps to ensure that health care personnel in residential care homes have sufficient knowledge of human rights obligations and national legislation on the use of coercion and force, including how to assess whether a patient has the capacity to consent, what is a valid consent, and in which circumstances the use of coercion and force can be permitted as a means of last resort.

[27] "Summary of National Supervision in 2011 and 2012 with Compulsory Health Assistance for Patients in Nursing Homes" from April 2013.

[28] "Thematic report: Human rights in Norwegian nursing homes" (2014), Norwegian Centre for Human Rights at the University of Oslo (NHRI 2001-2015). The report also suggested that documented practices also could be problematic in light of ECHR Article 3 and ICESCR Article 12.

[29] "Human Rights Situation of residents in nursing homes», B. Otnes, Statistics Norway, Document 2018/28.

4. Education of children with special needs

Reference is made to List of Issues para. 19 and the State's corresponding reply.

The Ombudsman for Children's thematic report from 2017 shows that many children with special education needs do not receive adequate standard of education and have low learning outcomes.[30] Schools generally have low expectations of these pupils. A large proportion of special education is provided by unskilled assistants and by teachers without the appropriate training, and the tendency has increased over time. The school administrations often receive inadequate needs assessment of children made by the educational and psychological counselling services (PPT). The PPT services do not always sufficiently map the learning potential of the pupils and seldom consult with them about the content or organization of their education.

Norwegian legislation provides rights for pupils with special education needs, many of whom fall within the scope of the CRPD.[31] Over several years, public inspections and research have documented a low level of understanding and adherence to the regulations.[32] Complaints and supervisory systems are largely inaccessible to children, the proceedings can take a long time and children are rarely heard. There are no sanctions or other effective instruments in relation to schools that do not comply with the law.

Suggested recommendations:

- The State Party should implement measures to ensure that children with special needs are provided with adequate education by qualified school personnel.
- The State Party should further strengthen the educational and psychological counselling services (PPT), establish national standards for special education as well as make special needs education a mandatory part of teacher education.
- The State Party should ensure that children with special educational needs have accessible complaint mechanisms, including effective sanctions for non-compliance.

[30] The Ombudsman for Children in Norway's report (2017): Students with Special Education Needs http://barneombudet.no/wp-content/uploads/2017/03/Bo_rapport_enkeltsider.pdf

[31] The Education act § 5-1.

[32] See The Norwegian Directorate for Education and Training (2015): Supervision with guidance creates change; The County Governors' supervision of the education and day-care areas in 2015; and The Ombudsman for Children in Norway's report (2017).