

# IDA's Compilation of CRPD Committee's Concluding Observations

Article 22 CRPD (Respect for privacy)

April 2024

# Article 22 - Right for privacy

- 1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.
- 2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

AZERBAIJAN (2024)

**BAHRAIN** (2024)

**KAZAKHSTAN (2024)** 

NICARAGUA (2024)

**SWEDEN (2024)** 

**ZAMBIA (2024)** 

**ANDORRA (2023)** 

**AUSTRIA (2023)** 

**GERMANY (2023)** 

**ISRAEL (2023)** 

**MALAWI (2023)** 

**MAURITANIA** (2023)

**GEORGIA (2023)** 

**PERU (2023)** 

**TUNISIA (2023)** 

**CHINA (2022)** 

**JAPAN (2022)** 

LAO PEOPLE'S DEMOCRATIC REPUBLIC (2022)

**REPUBLIC OF KOREA (2022)** 

SINGAPORE (2022)

SWITZERLAND (2022)

**FRANCE (2021)** 

INDIA (2019)

**SPAIN (2019)** 

**LATVIA (2017)** 

**ARMENIA (2017)** 

**UGANDA (2016)** 

**DENMARK (2014)** 

Please note there are no recommendations in the Concluding Observations on art. 22 on Costa Rica (2024), Mongolia, Paraguay, Angola, Argentina, Togo, New Zealand, Djibouti, Estonia, Cuba, Niger, Norway, Rwanda, Saudi Arabia, Senegal, Turkey, Vanuatu, The Former Yugoslav Republic of Macedonia, South Africa, Poland, Philippines, Malta, Bulgaria, Algeria, Haiti, Nepal, Oman, Russian Federation, Seychelles, Slovenia, Sudan, Luxembourg, Montenegro, Morocco, Panama, United Kingdom of Great Britain and Northern Ireland, Bosnia and Herzegovina, Canada, Cyprus, Honduras, Iran (Islamic Republic of), Jordan, Republic of Moldova, Bolivia, Colombia, Ethiopia, Guatemala, Italy, United Arab Emirates, Uruguay, Chile, Lithuania, Portugal, Serbia, Slovakia, Thailand, Brazil, European Union, Gabon, Kenya, Mauritius, Qatar, Ukraine, Cook Islands, Croatia, Czech Republic, Dominican Republic, Germany, Mongolia, Turkmenistan, Belgium, Ecuador, Mexico, New Zealand, Republic of Korea, Sweden, Azerbaijan, Costa Rica, Australia, Austria, El Salvador, Paraguay, Argentina, China, Hungary, Peru, Spain, Tunisia, Hungary, Jamaica, Mexico, Venezuela, Bangladesh, Indonesia and New Zealand.

# Azerbaijan (2024)

- 49. The Committee is concerned about the lack of information concerning protection of personal data and records about persons with disabilities, including health related situations.
- **50. The Committee recommends that the State party:**
- (a) Protect the right of persons with disabilities to respect for privacy, family life, correspondence, honour and reputation on an equal basis with others, regardless of disability, sex, gender, age and place of residence;
- (b) Introduce the duty for public and private actors to safeguard personal data, digitalized databases and records of persons with disabilities from unlawful and arbitrary interference, including health records and rehabilitation-related information;
- (c) Ensure implementation of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (CETS No. 108) and ratify the Protocol amending it (CETS No. 223) amendments to the Council of Europe Convention 108+.

## Bahrain (2024)1

The Committee is concerned about the following:

- (a) The exceptions contained in Law No. 30 of 2018 promulgating the Personal Data Protection Law in its fifth article, which allows access to and processing of personal data without the consent of the data subject, including its classification, use and disclosure to third parties, for the purposes of medical diagnosis, treatment and prevention, as well as for persons under guardianship and trusteeship; (b) The lack of mechanisms to protect the personal data of persons with disabilities who are users of mental health services and in care homes and beneficiaries of the disability allowance.
- (b) The lack of personal data protection mechanisms for persons with disabilities using mental health services, in care homes, and benefiting from the disability allowance.
- 45. The Committee recommends that the State party
- (a) Repeal the exceptions contained in the Personal Data Protection Law No. 30 of 2018 that allow access, circulation, disclosure and publication of data without the consent of the data subject for the purposes of diagnosis, treatment and prevention and for those under guardianship and wardship;
- (b) Develop a clear and accessible mechanism to protect the personal data of persons with disabilities who are users of mental health services, care homes and beneficiaries of the disability allowance.
- (c) Develop a clear and accessible mechanism for persons with disabilities to protect their personal data and report any breaches of privacy.

#### Kazakhstan (2024)

- 47. The Committee is concerned about:
- (a) Cross-border processing of personal data of persons with disabilities accessing medical, health and rehabilitation services and of information on their health to third countries, and its impact on the right to privacy of persons with disabilities.
- 48. The Committee recommends that the State party strengthen legal provisions for the protection of personal data and privacy of persons with disabilities, including by establishing safeguards in the Law on Online Platforms and Online Advertising and other relevant legislation, setting up data protection protocols and secure systems to guarantee the privacy of personal, health and rehabilitation information of persons with disabilities, and by providing effective remedies for breaches of privacy.

<sup>&</sup>lt;sup>1</sup> When compiling the recommendations, the Concluding Observations were only available in Arabic. This document includes an automated translation to English by <u>Deepl</u>.

#### Nicaragua (2024)

- 46. Al Comité le preocupa que no exista la información necesaria en formatos y modos alternos de comunicación y/o intérpretes de lengua de señas nicaragüense, lo que obliga a las personas con discapacidad a recurrir a terceros en sus asuntos judiciales, bancarios y crediticios, correspondencia privada o a asuntos de otra índole, violando su derecho a la privacidad contemplado en el artículo 27 de la Ley de los Derechos de Personas con Discapacidad (Ley 763).
- 47. El Comité recomienda al Estado parte que implemente los artículos 24 y 27 de la Ley de los Derechos de Personas con Discapacidad (Ley 763) y tome medidas para que el uso de formatos de comunicación accesibles, como el braille, la lengua de señas, los formatos de lectura fácil, el lenguaje sencillo, la audio descripción, la transcripción en vídeo, el subtitulado para personas sordas y los medios de comunicación táctiles, alternativos y aumentativos, estén disponibles para las personas con discapacidad cuando los requieran para poder acceder a las diferentes instituciones con respeto a su privacidad.

#### Sweden (2024)

- 49. The Committee is concerned about the lack of comprehensive measures ensuring data protection and the right to privacy concerning the personal, medical and rehabilitation information of persons with disabilities, in particular with regard to assessments of needs for services, including personal assistance.
- 50. The Committee recommends that the State party adopt all necessary measures, including the revision of data protection laws, to ensure data protection and the right to privacy, and set up data protection protocols and secure systems to guarantee the privacy of the personal, health and rehabilitation information of persons with disabilities, on an equal basis with others.

## Zambia (2024)

- 43. The Committee notes with concern the absence of provisions to protect the privacy of persons with disabilities in the Persons with Disabilities Act, the National Policy on Disability or any legislation.
- 44. The Committee recommends that the State party amend its national legislation to introduce legal provisions to protect the privacy of all persons with disabilities in all situations, in line with the Convention.

# **Andorra** (2023)

- 45. The Committee expresses its concern about insufficient protection of data of persons with disabilities in the health-care system, including in private practices, hospitals and institutions.
- 46. The Committee recommends that the State party implement effective measures to ensure the privacy of persons with disabilities, in particular persons with intellectual and/or psychosocial disabilities, including the confidentiality of information and of their personal medical records, in institutions and mental health systems and services.

## <u>Austria (2023)</u>

- 51. The Committee is concerned about:
- (a) The constraints for persons with disabilities in institutions to decide on and enter into a personal relationship, especially same-sex relationships, largely due to a lack of privacy and stymieing interference by personnel and legal representatives;
- (b) The deterring effect of anti-prostitution laws of the Länder on publicly funded facilitation services of sexual companionship for persons with disabilities.
- 52. The Committee recommends that the State Party:

- (a) Ensure respect for the right to private life, including sexual self-determination, of persons with disabilities living in institutions, and end deterring interference by personnel and quardians;
- (b) Harmonize federal and Länder legislation on prostitution and sexual companionship to ensure the provision of publicly funded facilitation services of sexual companionship for persons with disabilities.

#### <u>Germany (2023)</u>

- 49. The Committee is concerned about the lack of comprehensive measures ensuring data protection and the right to privacy concerning personal, medical and rehabilitation information of persons with disabilities in institutions and sheltered workshops, and the absence of confidentiality protocols concerning data protection of disability certificate holders vis-à-vis data exchange amongst institutions and service providers.
- 50. The Committee recommends that the State party adopt all necessary measures, including the revision of data protection laws, to ensure the data protection and the right to privacy in hospitals, institutions and sheltered workshops, and set up data protection protocols and secured systems to guarantee the privacy of personal, health and rehabilitation information of persons with disabilities, on an equal basis with others.

#### <u>Israel (2023)</u>

- 47. The Committee is concerned that the medical records and personal data of persons with psychosocial disabilities who are current or former patients of the Sheba Medical Center have been released to doctors without the consent of patients and without notification of this disclosure of information.
- 48. The Committee calls upon the State party to recall medical records and personal data of current and former patients of the Sheba Medical Center, strengthen and adopt data and privacy protection measures, including in relation to arbitrary or unlawful interference, and provide information about this situation and a formal apology to current and former patients.

## Malawi (2023)

- 45. The Committee is concerned about the absence of provisions regarding the protection of privacy of persons with disabilities, in areas, such as health care, support services for persons with disabilities, and other situations in which data is collected.
- 46. The Committee recommends that the State party make provision in law for the protection of the privacy of all persons with disabilities in all situations in line with the Convention.

# Mauritania (2023)

- 37. The Committee is concerned about the lack of information related to the laws on data protection and the lack of awareness on the part of persons with disabilities about their rights to data protection and privacy.
- 38. The Committee recommends that the State party:
- (a) Adopt measures to train and sensitize persons with disabilities and their families with regard to the legislation on the protection of personal data;
- (b) Raise awareness among persons with disabilities, and their representative organizations, as well as their families, on the respect for privacy and data protection;
- (c) Set up a national strategy, in close consultation with, and the active involvement of, persons with disabilities through their representative organizations, to ensure the respect for their privacy and the protection of their personal data as well as of their families.

#### **Georgia** (2023)

- 45. The Committee expresses concern about the lack of comprehensive measures ensuring data protection and privacy practices in hospitals and institutions for persons with disabilities.
- 46. The Committee recommends that the State party review and revise the Law on Personal Data Protection to include data protection and privacy practices of hospitals and institutions and set up data protection protocols in both health and institutions for persons with disabilities, guaranteeing the privacy of personal, health and rehabilitation information of persons with disabilities, on an equal basis with others.

#### Peru (2023)

- 44. Preocupa al Comité que el Registro Nacional de Identificación y Estado Civil (RENIEC), a petición de empresas privadas, facilita, sin previo consentimiento informado, datos confidenciales de personas con discapacidad e información sensible, lo que supone una clara violación de su derecho a la privacidad con altas posibilidades de excluirles de algunos servicios que prestan estas empresas por razón de su discapacidad.
- 45. El Comité recomienda al Estado parte que prohíba expresamente en la ley al Registro Nacional de Identificación y Estado Civil (RENIEC) la divulgación a terceros de datos de su registro, incluidos los datos relacionados con la discapacidad de las personas, a través de su sistema, y que se adopten disposiciones de confidencialidad y privacidad, incluidas medidas correctivas para dichas infracciones.

## **Tunisia** (2023)

- 39. The Committee is concerned about the lack of information related to the laws on data protection and the lack of awareness on the part of persons with disabilities about their right to data protection and privacy.
- 40. The Committee recommends that the State party:
- (a) Adopt measures to train and sensitize persons with disabilities and their families with regard to the legislation on the protection of personal data;
- (b) Raise awareness among persons with disabilities and their representative organisations as well as their families on the respect for privacy and data protection;
- (c) Set up a national strategy, with close consultation with and meaningful involvement of persons with disabilities and their representative organizations, to ensure the respect for their privacy and protection of their personal data as well as of their families.

## China (2022)

- 46. The Committee is concerned about the insufficient information provided on measures taken to protect persons with disabilities from arbitrary or unlawful interference with their privacy, to protect the privacy of personal data and records of persons with disabilities from arbitrary or unlawful interference, including in the registration system of persons with "mental disorders", and on the available remedies in case of violation of the right to privacy.
- 47. The Committee recommends that the State party ensure that the privacy of personal data of persons with disabilities is comprehensively protected by data protection laws across the State party, including a right of action and access to a remedy.

# Japan (2022)

47. The Committee is concerned that information about persons with disabilities may be collected without neither their consent nor reasonable purpose by service providers within private and public sectors, and that confidentiality and the protection of privacy of persons

with disabilities are not fully ensured by existing legislation, including the My Number Act and the Act on the Protection of Personal Information.

48. The Committee recommends that the State party strengthen its legislation on data protection for persons with disabilities by ensuring that it is processed either on the basis of the personal, free and informed consent of the data subject or other legitimate non-discriminatory basis laid down by law, and that it is collected for explicit, specified and legitimate purposes and not processed in a way incompatible with those purposes, that it is processed lawfully, fairly and in a transparent manner, and that the data subject has a right to an effective remedy.

#### Lao People's Democratic Republic (2022)

- 40. The Committee is concerned about the lack of information in the State party on progress made as regards the protection of the right to privacy of persons with disabilities.
- 41. The Committee recommends that the State party ensure the privacy of persons with disabilities, in particular persons with intellectual and/or psychosocial disabilities, including the confidentiality of information and of their personal medical records, in institutions and mental health systems and services.

#### Republic of Korea (2022)

- 45. The Committee observes with concern that in order to prevent disappearances GPS tracking devices are being issued to autistic persons, persons with intellectual and/or psychosocial disabilities without their free and informed consent, violating their right to privacy.
- 46. The Committee recommends that the State party:
- (a) Take measures to respect the privacy of persons with disabilities, in particular autistic persons, persons with intellectual disabilities, persons with psychosocial disabilities, neurodivergent persons, and to ensure that GPS tracking devices are issued based on their consent;
- (b) Take appropriate measures, including policies to prevent disappearances, which are in line with the Convention and the human rights model of disability.

# Singapore (2022)

- 43. The Committee is concerned about the protection of data of persons with disabilities in the health care system, including in private practices, hospitals and institutions. It is also concerned about practices that require persons with disabilities to disclose their impairments in relationships with private entities such as employers and insurance providers.
- 44. The Committee recommends that the State party substantially strengthen its legislation on data protection for persons with disabilities, particularly in the health care system, by ensuring that it is processed either on the basis of the personal, free and informed consent of the data subject or some other legitimate non-discriminatory basis laid down by law, and that it is collected for explicit, specified and legitimate purposes and not processed in a way incompatible with those purposes, that it is processed without discrimination, lawfully, fairly and in a transparent manner, and that the data subject has a right to an effective remedy.

# Switzerland (2022)

- 43. The Committee notes with concern:
- (a) The unnecessarily large amount of personal data required from persons with disabilities who apply for social insurance and other entitlements;

- (b) The lack of a right of action, given that the Disability Discrimination Act does not apply to services provided by cantons and municipalities.
- 44. The Committee recommends that the State party:
- (a) Ensure, through legislation and policy at the federal and cantonal levels, that data collection is limited to data that are specifically relevant, that personal data are disclosed with the consent of the individual only, and that data protection covers the personal data of those living in institutions;
- (b) Ensure that the privacy of the personal data of persons with disabilities is comprehensively protected by data protection laws across all cantons, including a right of action and access to remedy.

## <u>France (2021)</u>

- 46. The Committee notes with concern provisions in the Decree 2019-412 of 2019 and the Decree 2018-383 of 23 2018, so-called HOPSYWEB hindering the protection of personal data particularly concerning persons with psychosocial disabilities relating them with high risk of radicalisation and terrorism, and reinforcing surveillance and control of their activities, in the areas of employment and public housing.
- 47. The Committee recommends that the State party repeal regulations and cease discriminatory data collection concerning persons with psychosocial disabilities, including in relating them with high risk of radicalisation and terrorism, and prevent the use of their personal data and their medical records without their consent or following the consent provided by third parties.

#### India (2019)

- 46. The Committee is concerned that persons with disabilities who are Aadhaar (unique identification number) holders have experienced interference in their privacy, with their personal data having been compromised.
- 47. The Committee recommends that the State party take measures to ensure that all identification processes guarantee individuals' privacy, and enact legislation for the protection of the privacy of person with disabilities, particularly in their interaction with service providers or personnel providing support.

# Spain (2019)

- 41. The Committee is concerned that the right to privacy of persons with intellectual or psychosocial disabilities is widely violated in institutions and mental health facilities, including by depriving persons of their personal belongings, and an inflexible and minimal regime of visits and contacts with people outside the facilities. The Committee is also concerned by reports of video surveillance cameras placed in the rooms of patients and leaks of confidential information about patients through the mental health care sector.
- 42. The Committee recommends that the State party implement effective measures to ensure the privacy of persons with intellectual or psychosocial disabilities in institutions and mental health systems and services including the confidentiality of information and of their personal medical records.

# Latvia (2017)

- 36. The Committee is concerned about:
- (a) The lack of safeguards in place to protect the privacy of persons with psychosocial and/or intellectual disabilities who are listed on the register of patients suffering from certain diseases and the consequent adverse impact of being so listed when accessing particular services or applying for jobs;

- (b) The allegedly ineffective means of recourse to contest third-party access to the personal data of persons with intellectual and/or psychosocial disabilities that is collected by hospitals without the authorization of the individuals concerned;
- (c) The practice of public officials demanding medical certificates as proof of disability and their consequent disregard of State-issued disability certificates.
- 37. The Committee recommends that the State party:
- (a) Reinforce the protection of privacy, including personal data, in, among other places, psychiatric hospitals and institutions;
- (b) Improve public officials' awareness of a human rights-based approach to disability and sanction the reported practice of demanding medical certificates to prove disability.

## <u>Armenia (2017)</u>

- 37. The Committee is concerned that children with disabilities are publicly displayed for medical or charity purposes.
- 38. The Committee recommends that the State party protect the privacy of all children with disabilities, in particular in relation to their personal, health, habilitation and rehabilitation status.

## <u>Uganda (2016)</u>

- 44. The Committee is concerned about the lack of provision of sign language interpreters and information in accessible formats in the health and banking sectors.
- 45. The Committee recommends that the State party ensure the protection of personal data of persons with disabilities in protocols in the health and banking sectors.

## **Denmark** (2014)

- 50. The Committee is concerned that psychiatric hospitals are allowed, under the Psychiatric Act, to transfer strictly private and confidential information to third parties without the consent of the person concerned.
- 51. The Committee recommends that the State party amend the Psychiatric Act so as to prohibit the transfer of the private and confidential information of patients in psychiatric hospitals to third parties without the consent of the person concerned, in order to comply with the principle of respect for privacy.