**Article 22 - List of illustrative indicators on respect for privacy**

**Right to privacy**

**Attributes/Indicators**

* **Protection against unlawful or arbitrary interferences with privacy and of personal information**
* **Disclosure of disability related personal information**

**Structure**

22.1 Legislation recognizing and regulating the right to privacy, which is inclusive of persons with disabilities.[[1]](#endnote-1)

22.2 Legislation ensuring protection of and access to personal information, which is inclusive of persons with disabilities, on equal basis with others.[[2]](#endnote-2)

22.3 No provision in legislation or regulations that restricts protection of privacy and/or access to and protection of personal information, on the basis of disability.[[3]](#endnote-3)

22.4 Legislation regulating the confidentiality of disability related and health related personal information which protects against:

- unjustified forced disclosure by persons with disabilities of disability related[[4]](#endnote-4) and health related personal information, which might also lead to discriminatory practices;[[5]](#endnote-5) and

- the transfer and use of disability related and health related personal information among third parties without the prior, free and informed consent of the person concerned.[[6]](#endnote-6)

**Process**

22.5 Awareness raising campaigns and activities on the respect for privacy of persons with disabilities, targeting persons with disabilities, their families, public officials and private actors who keep records of personal information of persons with disabilities, and the general public.

22.6 Adoption of guidance materials and protocols for public officials and for staff of private services and institutions who keep records of personal information of persons with disabilities, for the respect and protection of privacy and access to and protection of personal information, which are inclusive of persons with disabilities (e.g. in the health and banking sectors.)

22.7 Number of private actors, notably health services and rehabilitation services providers and institutions, that have adopted a policy on respect for privacy, which is inclusive of persons with disabilities, including by addressing unjustified forced disclosure by persons with disabilities of disability related, and health related personal information.

22.8 Proportion of public officials trained on the respect of confidentiality of disability related personal information, disaggregated by relevant institution or agency.

22.9 Consultation processes undertaken to ensure active involvement of persons with disabilities, including through their representative organizations, in the design, implementation and monitoring of laws, regulations, policies and programs related to the respect for privacy of persons with disabilities.

22.10 Number of received complaints on the right to privacy, investigated and adjudicated in favor of the complainant, disaggregated by kind of mechanism, and the proportion of these complied with by the government or duty bearer.

**Outcome**

22.11 Number and proportion of persons with disabilities who report interference with their privacy by both public and private actors.[[7]](#endnote-7)

22.12 Number and proportion of persons with disabilities, victims of violations to the right to privacy who received compensation per year.

22.13 Number and proportion of persons with disabilities who report having been requested to disclose disability related and health related information, disaggregated by age, sex, disability and kind of actor that requests the disclosure.[[8]](#endnote-8)

**ANNEX**

1. Such legislation should ensure protection against arbitrary or unlawful interference with privacy, family, home or correspondence and from unlawful attacks on their honor and reputation; including e.g. measures to protect the right to image of persons with disabilities on an equal basis with others, including seeking to prevent and sanction practices such as the use of the image of children with disabilities for public display for medical and charity purposes. [↑](#endnote-ref-1)
2. Such legislation should include:

   - the right of persons with disabilities to access their own personal information in control of others(e.g. institution that prevents persons with disabilities to access their records, and issue of accessible formats to prevent need of other people);

   - the duty of State agencies and private actors that keep records of personal information, to ensure the availability of the information in accessible formats for persons with disabilities;

   - the right to request the rectification of information, on equal basis with others.

   - the prohibition of practices that interfere with the privacy of persons with disabilities in institutional settings, such as the deprivation of personal belongings, an inflexible and minimal regime of visits and contacts with people outside the facilities, videosurveillance, etc.. [↑](#endnote-ref-2)
3. In particular, no provision should establish any restriction to the access of personal information:

   Of persons with disabilities currently deprived of their legal capacity in contradiction with Article 12.

   Of persons with disabilities who are currently deprived of liberty on the basis of actual or perceived disability, in contradiction with Article 14 (e.g. in psychiatric inpatient settings)

   On the basis of actual or perceived disability, either alone or in combination with other grounds (e.g. protection). [↑](#endnote-ref-3)
4. E.g. In a given context, if accreditation of disability is needed to access a benefit or service, the sole certification/recognition of being a person with disability by a public authority or body should be sufficient (e.g. a disability card), and there should be no need to disclose the full disability assessment. [↑](#endnote-ref-4)
5. Legislation should explicitly indicate the cases in which disability related and health related information might be required and for what purpose, in order to prevent discrimination on the basis of disability. E.g. In the area of employment, disability related and health-related data could be sought from a job applicant once that person is offered the job, and for the sole purpose of providing reasonable accommodation, if required. [↑](#endnote-ref-5)
6. Such legislation should include safeguards to prevent third parties from accessing information in order to prevent misuse or potential negative consequences, e.g. using information to determine obtaining a job or accessing services. [↑](#endnote-ref-6)
7. Such an indicator could be develop based on statistical data produced by household surveys or specific disability survey by addressing privacy concerns. [↑](#endnote-ref-7)
8. Such an indicator could be develop based on statistical data produced by household surveys or specific disability survey by addressing privacy concerns. [↑](#endnote-ref-8)