Article 22: Illustrative indicators on respect for privacy

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<tr><th colspan="3">Article 22: Illustrative indicators on respect for privacy</th></tr>
<tr><th colspan="3">Right to privacy</th></tr>
<tr><th>Attribute/type of indicator</th><th>Protection against unlawful or arbitrary interferences with privacy and access to personal information</th><th>Disclosure of disability-related personal information and data</th></tr>
<tr><td>Structure</td><td>22.1: Legislation recognizing and regulating the right to privacy that is inclusive of persons with disabilities[a]
22.2: Legislation ensuring access to personal information that is inclusive of persons with disabilities on an equal basis with others[b]
22.3: No provisions in legislation or regulations that restrict protection of privacy or access to personal information on the basis of disability[c]</td><td>22.4: Legislation regulating the confidentiality of disability-related and health-related personal information and data that protects against:
Unjustified disclosure by persons with disabilities of disability-related and health-related[d] personal information[e]
Transfer and use of disability-related and health-related personal information and data among third parties without the free and informed consent of the person concerned[f]</td></tr>
<tr><td rowspan="2">Process</td><td colspan="2">22.5: Number of awareness-raising campaigns and activities on the respect for privacy of persons with disabilities targeting persons with disabilities, their families, the general public, public officials and private actors who keep records of personal information on persons with disabilities, and proportion of population who gained access to those campaigns and activities, disaggregated by age, sex, disability and geographical location
22.6: Number of guidance materials and protocols adopted on the respect for and protection of privacy and access to personal information that are inclusive of persons with disabilities, targeting staff of public and private services and institutions keeping records of personal data on persons with disabilities (e.g. health sector and banking sector)
22.7: Number of private actors, notably health and rehabilitation service providers and institutions, that have adopted a policy on respect for privacy that is inclusive of persons with disabilities, including by addressing unjustified disclosure of disability-related and health-related personal information
22.8: Proportion of public officials trained on respect for the privacy of persons with disabilities and the confidentiality of disability-related and health-related personal information, disaggregated by relevant institution or agency</td></tr>
<tr><td colspan="2">22.9: Number of consultation processes undertaken on the design, implementation and monitoring of laws, regulations, policies and programmes related to respect for privacy, including of persons with disabilities, and proportion of persons with disabilities who participated in those processes, disaggregated by age, sex, disability and geographical location[g]
22.10: Proportion of complaints received on the right to privacy of persons with disabilities that have been investigated and adjudicated; proportion of those found in favour of the complainant; and proportion of the latter that have been complied with by the Government and/or duty bearer; each disaggregated by type of mechanism</td></tr>
<tr><td>Outcome</td><td colspan="2">22.11: Number and proportion of persons with disabilities who report interference with their privacy by both public and private actors[h]
22.12: Number and proportion of persons with disabilities who are victims of violations of the right to privacy who received compensation per year</td></tr>
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[a] Such legislation should ensure protection against arbitrary or unlawful interference with privacy, family, home or correspondence, and from unlawful attacks on their honour and reputation, including measures to protect the right to the image of persons with disabilities on an equal basis with others, and seeking to prevent and sanction practices such as the non-consensual use of the image of children with disabilities, for example, for public display for medical and charity purposes. Such legislation should also apply to temporary or long-term residential settings, including prohibiting practices that interfere with the privacy of persons with disabilities, such as the deprivation of personal belongings, restrictions of visits and contacts with people outside the facilities, video surveillance and so forth.

[b] Such legislation should include:

- The right of persons with disabilities to have access, on an equal basis with others, to their personal information that is held or controlled by others. Any restrictions cannot be based on actual or perceived disability (e.g. an institution cannot prevent persons with disabilities from having access to records concerning them)
- The duty of State agencies and private actors that hold records of personal information to ensure the availability of information in accessible formats for persons with disabilities who request them
- The right to request the rectification of information on an equal basis with others

[c] In particular, no restriction on the access of personal information:

- By persons with disabilities currently deprived of their legal capacity (in contradiction with article 12 of the Convention on the Rights of Persons with Disabilities)
- By persons with disabilities currently deprived of liberty on the basis of actual or perceived disability (in contradiction with article 14 of the Convention; e.g. in psychiatric inpatient settings)
- On the basis of actual or perceived disability, either alone or in combination with other grounds (e.g. for their own protection or best interest)
- On the basis of perceived limitations in decision-making or on the basis of a mental capacity assessment, alone or in combination with other grounds (e.g. for their own protection or best interest)

[d] For example, in a given context, if certification of disability is required to gain access to a benefit or service, recognition by a public authority or body, such as through the presentation of a disability card or certificate, should be sufficient, and there should be no requirement to disclose the disability assessment upon which the certification is based.

[e] Legislation should explicitly indicate the cases in which disability-related and health-related information may be required and for what purpose in order to prevent discrimination on the basis of disability. For example, 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.

[f] Such legislation should include safeguards to prevent third parties from gaining access to information and to prevent misuse or potential negative consequences, such as the misuse of information in recruitment processes to disqualify candidates with disabilities.

[g] This indicator requires verifying concrete activities undertaken by public authorities to involve persons with disabilities in decision-making processes related to issues that directly or indirectly affect them in line with article 4 (3) of the Convention on the Rights of Persons with Disabilities and general comment No. 7 (2018) of the Committee on the Rights of Persons with Disabilities, including consultation meetings, technical briefings, online consultation surveys, and calls for comments on draft legislation and policies, among other methods and mechanisms of participation. In this regard, States must:

- Ensure that consultation processes are transparent and accessible
- Ensure the provision of appropriate and accessible information
- Not withhold information or condition or prevent representatives of persons with disabilities from freely expressing their opinions

- Include both registered and unregistered organizations
- Ensure early and continuous involvement of persons with disabilities
- Cover related expenses of participants

[h] Such an indicator could be developed based on statistical data produced by household surveys or disability-specific surveys by including issues related to privacy concerns.