

Article 22:

List of illustrative indicators on respect for privacy

ADVANCE VERSION

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The *Human Rights Indicators on the Convention on the Rights of Persons with Disabilities (CRPD)* are a component of the [SDG-CRPD Resource Package](#) developed by the Office of the United Nations High Commissioner for Human Rights (OHCHR). This is an advance version of the SDG-CRPD Resource Package. A final version will be issued upon completion of OHCHR review processes.

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Right to privacy

Attributes/ Indicators	Protection against unlawful or arbitrary interferences with privacy and access to personal information	Disclosure of disability-related personal information and data
Structure	<p>22.1 Legislation recognizing and regulating the right to privacy, which is inclusive of persons with disabilities.ⁱ</p> <p>22.2 Legislation ensuring access to personal information which is inclusive of persons with disabilities, on an equal basis with others.ⁱⁱ</p> <p>22.3 No provisions in legislation or regulations that restrict protection of privacy and/or access to personal information, on the basis of disability.ⁱⁱⁱ</p>	<p>22.4 Legislation regulating the confidentiality of disability-related and health-related personal information and data which protect against:</p> <ul style="list-style-type: none"> • unjustified disclosure by persons with disabilities of disability- and/or health-related^{iv} personal information;^v and • the 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.^{vi}
Process	<p>22.5 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.</p> <p>22.6 Adoption of guidance materials and protocols on the respect and protection of privacy and access to personal information, which 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, banking sector)</p> <p>22.7 Number of private actors, notably health and rehabilitation service providers and institutions, that have adopted a policy on respect for privacy which is inclusive of persons with disabilities, including by addressing unjustified disclosure of disability-related, and health-related personal information.</p> <p>22.8 Proportion of public officials trained on the respect of privacy of persons with disabilities and the confidentiality of disability and health-related personal information, disaggregated by relevant institution or agency.</p> <p>22.9 Consultation processes undertaken to ensure the active involvement of persons with disabilities, including through their representative organizations, in the design, implementation and monitoring of laws, regulations, policies and programmes related to the respect for privacy of persons with disabilities.^{vii}</p> <p>22.10 Proportion of received complaints 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 kind of mechanism.</p>	
Outcome	<p>22.11 Number and proportion of persons with disabilities who report interferences with their privacy by both public and private actors.^{viii}</p> <p>22.12 Number and proportion of persons with disabilities, victims of violations to the right to privacy who received compensation per year.</p>	

- i 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 measures to protect the right to 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, etc.
- ii Such legislation should include:
- the right of persons with disabilities to access, on an equal basis with others, their personal information which 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 which 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.
- iii In particular, no restriction to the access of personal information:
- By persons with disabilities currently deprived of their legal capacity (in contradiction with Article 12);
 - By 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. for their own protection, best interest, etc.);
- 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, best interest, etc.).
- iv E.g. In a given context, if certification of disability is needed to access 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 need to disclose the disability assessment upon which the certification is based.
- v 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. 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.
- vi Such legislation should include safeguards to prevent third parties from accessing information and to prevent misuse or potential negative consequences, e.g. misuse of information in recruitment processes to disqualify candidates with disabilities.
- vii 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 CRPD and [General Comment no. 7](#) of the CRPD Committee, including consultation meetings, technical briefings, online consultation surveys, 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 provision of appropriate and accessible information;
- not withhold information, condition or prevent organizations of persons with disabilities from freely expressing their opinions;
 - include both registered and unregistered organizations;
 - ensure early and continuous involvement;
 - cover related expenses of participants.
- viii Such an indicator could be developed based on statistical data produced by household surveys or specific disability survey by addressing privacy concerns.