

Implementing the UN Convention on the Rights of Persons with Disabilities

Human rights indicators

Guidance for independent national monitoring frameworks





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Why this guidance?

This guide helps independent national monitoring frameworks to fulfil their monitoring responsibility set out in Article 33 of the Convention on the Rights of Persons with Disabilities (CRPD). It focuses on the use of indicators. It does not deal with aspects such as compliance with the Paris Principles or the efficiency of complaints mechanisms. Its objective is to support national monitoring frameworks in designing or improving indicators for assessing progress of CRPD implementation at national level.

Developing appropriate indicators and benchmarks is an integral part of national efforts to monitor the implementation of the rights enshrined in the CRPD and to measure progress towards the realisation of the CRPD commitments.

Indicators are not simply a set of benchmarks. They are instrumental in translating globally agreed standards into specific legal, policy-making and practical steps towards realising fundamental rights, so long as they are properly designed and used. In essence, indicators break down legal standards into measurable elements and clearly defined questions or lines of enquiry, into which quantifiable data and information are fed.

Indicators also support evidence-based policymaking grounded in human rights. They do so by enabling the identification of gaps and tracking of progress over time.

Indicator frameworks provide a solid evidence basis for the following groups to establish the extent of unequal outcomes and identify where policy intervention is required:

- policymakers;
- independent monitoring bodies;
- national human rights bodies;
- persons with disabilities and their representative organisations; and
- wider civil society.

Basis of this paper

This guide builds on guidance of the UN Committee on the Rights of Persons with Disabilities (CRPD Committee), notably the 'Guidelines on independent monitoring frameworks and their participation in the work of the Committee on the Rights of Persons with Disabilities',* and on the work of the Office of the United Nations High Commissioner for Human Rights (OHCHR) on human rights-based indicators and data collection.** It also builds on information that the European Union Agency for Fundamental Rights (FRA) gathered directly from national monitoring frameworks. FRA wishes to thank the Working Group on the Convention on Rights of Persons with Disabilities of the **European Network of National**

Human Rights Institutions (ENNHRI) for its cooperation in producing this guidance.

* UN Committee on the Rights of Persons with Disabilities (2016), Rules of Procedure of the Committee on the Rights of Persons with Disabilities-Annex-Guidelines on independent monitoring frameworks and their participation in the work of the Committee on the Rights of Persons with Disabilities, pp. 33-43.

** OHCHR (2012), <u>Human rights</u> indicators: A guide to measurement and implementation; OHCHR (2018), A human rights-based approach to data – Leaving no one behind in the 2030 Agenda for Sustainable Development.

Outline

Chapter 2 outlines the role of Article 33 (2) frameworks in monitoring the implementation of the CRPD.

Chapter 3 explores the States Parties' obligation to systematically collect robust and objective data. Such data collection is a prerequisite for assessing the impact of the implementation of legislation and policies.

Chapter 4 introduces the OHCHR-developed human rights-based indicators framework.

Chapter 5 highlights selected data collection mechanisms and sources.

Chapter 6 presents information about national practices from more than half of the Article 33 (2) frameworks in the European Union (EU) Member States gathered by FRA with the support of the ENNHRI <u>Working Group on the Convention on Rights of Persons with Disabilities</u> of ENNHRI. Article 33 (2) bodies from the following EU countries did not provide information: Belgium, Croatia, Cyprus, Finland, Germany, Greece, Hungary, Romania and Slovakia. It is important to note that some national monitoring

frameworks were designated or created in recent years, and not all of them have been able to start working extensively with indicators, for example due to limited resources.

Chapter 7 outlines some main challenges and practical ways forward reported by the Article 33 (2) bodies that provided information for this quide.

Monitoring CRPD implementation through the EU Framework for the CRPD

In 2010, the EU acceded to the CRPD, making it the first legally binding international human rights instrument to which the Union is party. In 2013, the Council of the EU put in place a mechanism: the EU Framework for the UN Convention on the Rights of Persons with Disabilities.

As Article 33 (2) of the Convention requires, the EU Framework is to promote, protect and monitor the implementation of the CRPD at EU level. It complements national monitoring frameworks, which are responsible for promoting, protecting and monitoring the CRPD at national level.

The EU Framework comprises four members: the European Parliament, the European Ombuds institution, FRA and the European Disability Forum. The EU Framework supports the EU's implementation of the CRPD in matters falling under EU competence, such as:

- EU law and policies (e.g. nondiscrimination in employment, passengers' rights and EU funding);
- EU public administration (e.g. EU personnel selection and access to documents).

According to their respective competences and mandates, the EU Framework members contribute collectively to the promotion, protection and monitoring of the implementation of the CRPD by the EU. As part of its contribution to the EU Framework's monitoring activities, FRA collects reliable, objective and comparable data across the EU, reports on developments in the implementation of the CRPD in its annual Fundamental Rights Report and, notably, develops human rights indicators to assess the implementation of those rights (see box 'The S-P-O model' in Chapter 4).

The EU Framework also contributes actively to the review of the EU's implementation of the CRPD. This review is carried out by the CRPD Committee – the 'treaty body' for the CRPD – which is responsible for assessing whether parties to the Convention are meeting their obligations under the CRPD.

For more information, see 'EU Framework for the UN Convention on the Rights of Persons with Disabilities'.

1 Role of independent national monitoring frameworks

Independent national monitoring frameworks are set up for the promotion, protection and monitoring of the CRPD implementation. The reference to specific requirements of national implementation and monitoring in Article 33 (2) of the CRPD underlines the importance of the Convention in driving reform, as States Parties strive to meet their obligations under the Convention.¹

In 2011, for the first time, the EU became a party to an international human rights treaty – the CRPD. In its declaration upon signature, the EU noted that "for the purpose of the Convention, the term 'States Parties' applies to regional integration organisations within the limits of their competence".

This guide uses the term 'States Parties' to include all parties to the treaty, not only 'states'.

The CRPD Committee stresses that national- and international-level monitoring should be "complementary and mutually reinforcing". Furthermore, it recognises the importance of national monitoring frameworks and the pivotal role they have to play in monitoring the CRPD implementation. This results from the frameworks' permanent nature and their "close connection with the national, regional and local setting in which the Convention is implemented".²

1.1. What to monitor?

The CRPD Committee sets out that policies and programmes should be designed, implemented, evaluated and monitored based on the human rights model of disability, which is enshrined in the Convention. Such policies and programmes should identify:

- gaps that prevent persons with disabilities as rights-holders from fully enjoying their rights;
- gaps that prevent duty-bearers from fully implementing their legal obligations to respect, protect and fulfil the rights of persons with disabilities.³

The CRPD Committee also clearly sets out that indicators should measure barriers, rather than impairment(s) to reflect the rights-based, social model of disability. This model views disability as a social construct based on an interaction between an impairment and societal barriers. It is important to measure the impairment only to the extent to which it affects the level of barriers people face.⁴

Measuring gaps in the enjoyment of fundamental rights between persons with and without disabilities is required to identify the necessary steps so that persons with disabilities enjoy their rights on an equal basis with others.

Indicators for monitoring purposes should also measure differences in outcomes among persons with disabilities. They should reflect differences in experiences and the variety and severity of barriers persons with different impairments face in their daily lives.

In addition, the CRPD Committee recommends that a "twin-track approach" to disability should be reflected in the monitoring of policies and programmes, and that monitoring activities should measure:

- the impact of "mainstream policies and programmes on persons with disabilities",
- the impact of "disability-specific policies".5

In practice, this means that monitoring the implementation of laws and policies at national, regional and local levels should cover not only disability-specific policies but also all mainstream policies, such as health, education, transportation and employment.

1.2. How to monitor?

→

Source: Rules of Procedure
of the Committee on
the Rights of Persons
with DisabilitiesAnnex-Guidelines on
independent monitoring
frameworks and their
participation in the work
of the Committee on the
Rights of Persons with
Disabilities, IV. 'Monitoring
implementation of the
Convention at the national
level', paragraphs 13
and 39.

Paragraph 13:

"Monitoring activities include developing a system to assess the impact of the implementation of legislation and policies; developing indicators and benchmarks; and maintaining databases containing information on practices related to the implementation of the Convention."

Paragraph 39 (g):

"Monitoring activities should not only focus on the results or outcomes of policies and programmes but also take into account the structural and policy frameworks and the processes in place to achieve such results."

The CRPD Committee sets out three main monitoring activities for the independent monitoring frameworks:

- developing a system to assess the impact of the implementation of legislation and policies;
- developing indicators and benchmarks;
- maintaining databases containing information on practices related to the implementation of the Convention.⁶

Developing indicators and benchmarks is therefore key to delivering on the EU Framework's responsibility to monitor the implementation of the rights enshrined in the CRPD. It is also key to measuring the progress of parties to the treaty in the realisation of their commitments.

Furthermore, the CRPD Committee explicitly "encourages independent monitoring frameworks to take into account the human rights-based approach to indicators developed by the OHCHR".7 Human rights-based indicators capture not only the results or outcomes of laws and policies on human rights situations of individuals. They also capture states' commitments (in terms of law and policy) and efforts (policy implementation) regarding the implementation of their obligations (see Chapter 4).

Thus, effective human rights monitoring – capturing the processes behind the outcomes in addition to the outcomes themselves – requires the use of both quantitative and qualitative indicators. Quantitative indicators are essentially numerical, involving 'statistics'. Qualitative indicators seek to capture, analyse and evaluate the state of implementation of obligations and of the realisation of human rights by using information beyond statistics. Quantitative and qualitative indicators are equally important given the complexity of assessing compliance with human rights standards: "quantitative indicators can facilitate qualitative evaluations by measuring the magnitude of certain events [and] qualitative information can complement the interpretation of quantitative indicators".8

2 Filling the gap in data

2.1. States Parties' obligation to collect data

Source: Article 31 of the CRPD

- 1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:
 - a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;
 - b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.
- 2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.
- States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Assessing the impact of the implementation of legislation and policies and monitoring progress on the ground require systematic collection of robust and objective data. The CRPD reflects the existing lack of data on the experiences of persons with disabilities. It places an explicit obligation on parties to the treaty: "collect appropriate information, including statistical and research data, to enable [parties to the treaty] to formulate and implement policies to give effect to the present Convention" (Article 31). This was the first time a UN human rights treaty included a specific article on statistics and data collection.

The CRPD Committee stresses the importance of a multi-tiered approach and "collective, coordinated and continuous efforts to improve the systems for collecting and analysing data". It further outlines a number of institutions and bodies with a role in the "systems for collecting and analysing data". In addition to the Article 33 (2) national frameworks, these institutions and bodies include:

- national statistical offices,
- the focal point and coordination mechanism appointed under Article 33 (1) of the CRPD,
- civil society organisations,
- organisations representing persons with disabilities.

National actors and data collection instruments that support – or could support – the attainment of more and better data to inform monitoring activities of Article 33 (2) frameworks are explored under Chapter 5.

2.2. Data gaps and challenges

Robust and reliable equality data (the definition of 'equality data' is provided in the box 'What are equality data?' in Chapter 5¹⁰) are a prerequisite for states to monitor the implementation of the CRPD. They are also necessary for monitoring, in a wider context, national and EU legislation and policies that promote equality and non-discrimination. When collected regularly and systematically, such information is essential for helping Member States assess their compliance with human rights obligations. However, few Member States operate comprehensive systems for or a coordinated approach to the collection and use of equality data and data on the situation of persons with disabilities.

The CRPD Committee has highlighted several additional challenges pertaining to the limited availability of reliable data on the situation of persons with disabilities. These include:

- lack of data disaggregated by type of disability, sex or age;
- data collection systems often being based on outdated approaches to disability, such as the medical model of disability;
- differences between methods and systems for assessing disability in different regions, and in different ministries and departments;
- no or insufficient participation of persons with disabilities and their representative organisations in the design and implementation of national census and household surveys;
- lack of systematic use of baselines, indicators and benchmarks in data collection and analysis activities.¹¹

The importance of these issues is further captured and stressed in recent concluding observations on Article 31 issued to States Parties by the CRPD Committee (see Table 1).

Table 1: Selected examples of the concluding observations (COs) on Article 31 of the CRPD issued to States Parties by the CRPD Committee

Issues addressed	Recommendations from the CRPD Committee to the State Party
Data collection	 "develop data collection systems on the situation of persons with disabilities [] These systems should cover all areas of life" (COs on France, paragraph 63, 4 October 2021) "establish a mandatory register for any forced treatment, including involuntary commitment, mechanical restraints, forced medication and electroconvulsive therapy, that occurs in mental health-care facilities" (COs on Spain, paragraph 59 (b), 13 May 2019) "establish a unified data-collection system that is in line with the Convention and takes into account the Washington Group Short Set of Questions on Disability" (COs on Malta, paragraph 46 (a), 17 October 2018)
Data disaggregation	 "[collect] data on persons with disabilities disaggregated by age, sex, sexual orientation, gender identity, race, ethnicity, income, migration status, level of education, employment situation and place of residence" (COs on Estonia, paragraph 61, 5 May 2021) "take measures to increase the availability of high-quality, timely and reliable disaggregated data" (COs on Bulgaria, paragraph 68 (b), 22 October 2018) "collect, analyse and disseminate disaggregated data on [] the barriers that persons with disabilities face in society and their level of poverty" (COs on Slovenia, paragraph 54 (b), 16 April 2018)
Intersectionality	• "Ensure that data-collection systems and impact assessments of legislation and policies include indicators and disaggregated data concerning women and girls with disabilities" (COs on France, paragraph 14 (a), 4 October 2021)

Issues addressed	Recommendations from the CRPD Committee to the State Party
Confidentiality and privacy	• "develop a system and procedures for collecting data [] [These] should ensure confidentiality and respect the privacy of persons with disabilities" (COs on Estonia, paragraph 61, 5 May 2021)
Independent and participatory approach	 "promote participatory research projects in cooperation with persons with disabilities on matters concerning them" (COs on France, paragraph 63, 4 October 2021) "support independent and participatory research, both quantitative and qualitative" (COs on Estonia, paragraph 61, 5 May 2021) "ensure the involvement of organizations of person[s] with disabilities in data collection, including in the development of the methodologies of data collection and in the data analysis process" (COs on Poland, paragraph 54 (c), 29 October 2018)
Accessibility	 "ensure the access of persons with disabilities to all statistical data in accessible formats" (<u>COs on</u> <u>Malta</u>, paragraph 46 (b), 17 October 2018)
Regular data collection	• "allocate funds to undertake periodic research on the rights of persons with disabilities" (COs on Estonia , paragraph 61, 5 May 2021)

Source: CRPD Committee concluding observations on Bulgaria, Estonia, France, Malta, Poland and Spain.

Gaps in national data collection systems are not restricted to the situation of persons with disabilities. There are broader gaps in the collection and use of equality data across the EU Member States. These range from lack of resources and investment in collecting equality data and insufficient comparability across different data sources, to challenges of a more technical nature, such as inaccurate interpretation of the EU data protection requirements under the EU General Data Protection Regulation.¹²

These shared challenges and the importance of equality data for enabling proper assessment of the implementation of the EU equality legislation and for monitoring trends in equality are acknowledged by the High Level Group on Non-discrimination, Equality and Diversity. The dedicated Subgroup on Equality Data, which FRA facilitates, was set up with the aim of supporting Member States to improve the collection and use of equality data. The subgroup has produced the following guidance, among other publications: Guidelines on improving the collection and use of equality data and Guidance note on the collection and use of equality data based on racial or ethnic origin. FRA also maintains an online compendium of practices for the collection and use of equality data.

Improving the collection and use of equality data at national level

The European Commission-issued <u>Guidelines on improving</u> <u>the collection and use of equality data</u> offer concrete guidance on improving the collection and use of equality data at national level. The following institutional, structural and operational guidelines for the collection and use of equality data are provided.

Institutional and structural guidelines

- Map existing sources of equality data and identify data gaps.
- Foster interinstitutional cooperation in the collection and use of equality data.
- Set up a data hub on equality and non-discrimination.
- Build institutional capacity to collect robust and reliable equality data.
- Facilitate effective use of equality data.

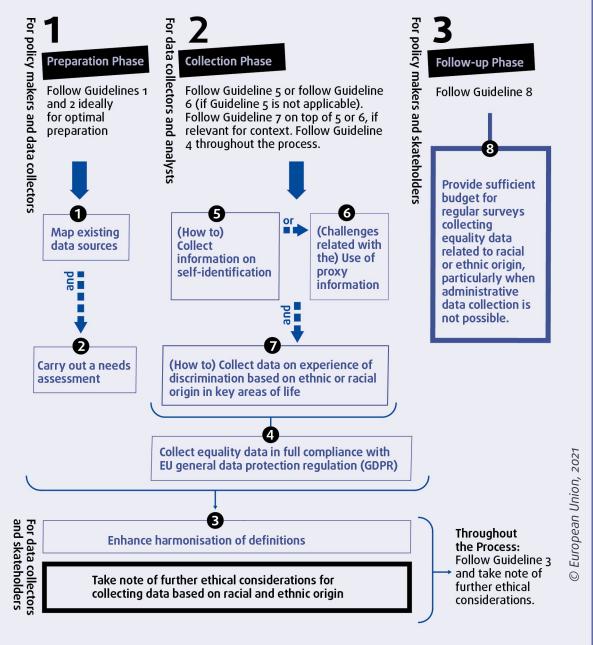
Operational guidelines

- Ensure comprehensiveness of equality data.
- Mainstream equality data into EU and national surveys.
- Ensure regular and timely equality data collection.
- Enhance validity and reliability of equality data.
- Ensure representativeness of equality data.
- Improve comparability of equality data.

The guidelines cover all stages of the process and aim to support and provide guidance to policymakers, data collectors, data analysts and relevant stakeholders throughout the preparation, collection and follow-up phases.

In addition, the Subgroup on Equality Data developed practical guidance on improving the collection and use of data disaggregated by racial or ethnic origin to support Member States' efforts in assessing the situation of ethnic minorities and other racial groups. The guidance aims to help relevant stakeholders identify disparities based on ethnic or racial origin. Another aim is to provide practical guidance on effective ways to produce comprehensive, reliable, comparable and regular data at national level.

Figure 1: Guiding principles for collecting equality data on racial or ethnic origin – sequence and possible combination



Source: Guidance note on the collection and use of equality data based on racial or ethnic origin, High Level Group on Non-discrimination, Equality and Diversity, Subgroup on equality data, Justice and Consumers, European Commission.

2.3. Utilising data and indicators for CRPD monitoring to inform other processes

Systematic collection of robust and objective data is not only required to inform monitoring of CRPD implementation. It is also indispensable to Member States for overall assessment of the implementation of relevant EU and national equality legislation. Moreover, it facilitates monitoring of trends and responding to requests for data to inform several other processes and policies at both UN and EU levels.

At UN level, data and indicators for monitoring CRPD implementation could support states in their efforts to assess progress towards achieving the UN Sustainable Development Goals (SDGs). Several SDGs explicitly mention persons with disabilities, despite there not being a specific SDG or SDG target on disability inclusion. Examples include the goals on quality education (SDG 4), job opportunities (SDG 8), economic, social, political and economic inclusion (SDG 10) and sustainable cities (SDG 11). Moreover, SDG Target 17.18 requires states to "increase significantly the availability of high-quality, timely and reliable data", disaggregated by disability among other things. A number of SDG indicators also refer to persons with disabilities (e.g. Indicators 1.3.1 and 16.7.1). This reflects the central principle of the 2030 Agenda for Sustainable Development: "leaving no one behind".

PROMISING PRACTICE

Bridging the gap: promoting an inclusive 2030 Agenda for Sustainable Development

The EU-funded project 'Bridging the Gap' aimed to support CRPD monitoring as part of the monitoring of progress towards the SDGs by developing human rights indicators based on the OHCHR methodology. The indicators were developed based on the CRPD, on the jurisprudence of the CRPD Committee and on other human rights standards. A participatory approach was used during their development. The following groups

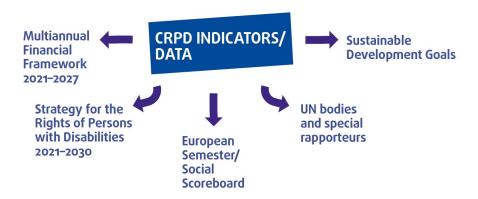
were consulted as part of the project: the CRPD Committee, the UN Special Rapporteur on the Rights of Persons with Disabilities, UN agencies, organisations of persons with disabilities, civil society organisations, national human rights institutions, academia and national statistical offices.

For more information, see the **Bridging the Gap project website**.

2.3.1. Indicators - a source of information

Similarly, indicators have frequently been used in States Parties' reports and by national human rights institutions when engaging with international human rights monitoring mechanisms, for example UN treaty bodies and special procedures (such as special rapporteurs). They have also been used by national human rights institutions when following up on recommendations made during the UN Universal Periodic Review.

Figure 2: CRPD indicators – a source of information for many processes



Source: FRA, 2023

Data and indicators on the implementation of the CRPD are relevant at EU level. They could inform and feed into Member States' reporting on a number of EU policies and processes. Notably, the Strategy for the Rights of Persons with Disabilities 2021–2030 aims to develop disability indicators and a monitoring framework for strategy-related activities. The developed monitoring dashboard aims to capture and present progress not only of the EU-level activities under the strategy but also of "those at the national level which the Commission calls on Member States for action". The EU-level activities under the strategy but also of "those at the national level which the Commission calls on Member States for action".

Data could also provide input for other frameworks, such as the European Semester and the EU Social Scoreboard, which accompany the European Pillar of Social Rights. ¹⁵ **The European Pillar of Social Rights**, adopted in 2017, sets out 20 principles for a "strong social Europe". The Social Scoreboard accompanying it tracks trends in Member States' performance across 12 indicators linked to the principles of the European Pillar of Social Rights.

Lastly, data and indicators pertaining to the implementation of the CRPD could support Member States in reporting on the fulfilment of the 'enabling conditions' set out in the Common Provisions Regulation 2021–2027. This regulation requires that Member States have a national framework to ensure implementation of the CRPD. This framework must include, among other things, "objectives with measurable goals [and] data collection and monitoring mechanisms". This is required for the fulfilment of the CRPD-related horizontal enabling condition "Implementation and application of the [CRPD] in accordance with Council Decision 2010/48/EC". This enabling condition is applicable to all specific objectives that the regulation lists.

The Common Provisions Regulation also sets out thematic enabling conditions linked to different funds (e.g. the European Regional Development Fund, the European Social Fund Plus and the Cohesion Fund). These conditions address specific objectives, including "promoting the transition from institutional to family-based and community based care" and "promotion of accessibility for persons with disabilities".

Using indicators and benchmarks to monitor the implementation of the CRPD is therefore not an isolated exercise. Ideally, their use will involve an exchange of ideas between those responsible for disability-sensitive monitoring obligations under the SDGs, the UN Universal Periodic Review and other UN human rights mechanisms. It will ideally also inform reporting processes at EU level, such as those on the implementation of the Strategy for the Rights of Persons with Disabilities 2021–2030, the EU Pillar of Social Rights and the European Semester. It can also provide information on the fulfilment of the enabling conditions for relevant funds under the current EU Multiannual Financial Framework 2021–2027 (e.g. the European Regional Development Fund, the European Social Fund Plus and the Cohesion Fund).

3 Using human rights-based indicators to assess progress in implementing fundamental rights obligations – OHCHR indicator framework

Paragraph 39 (g):

"Monitoring activities should not only focus on the results or outcomes of policies and programmes but also take into account the structural and policy frameworks and the processes in place to achieve such results. In that regard, the Committee encourages independent monitoring frameworks to take into account the human rights-based approach to indicators developed by the Office of the United Nations High Commissioner for Human Rights."

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Source: UN Committee on the Rights of Persons with Disabilities (2016), Rules of Procedure of the Committee on the Rights of Persons with Disabilities-Annex-Guidelines on independent monitoring frameworks and their participation in the work of the Committee on the Rights of Persons with Disabilities, IV. 'Monitoring implementation of the Convention at the national level', paragraph 39 (g).

The conceptual and methodological framework developed by OHCHR aims "to adopt a structured and consistent approach for translating universal human rights standards into indicators that are contextually relevant and useful at country level". OHCHR defines human rights indicators as "specific information on the state of an event, activity or outcome that can be related to human rights norms and standards; that address and reflect the human rights concerns and principles; and that are used to assess and monitor promotion and protection of human rights". 19

One principal feature of the OHCHR framework is that it recommends a configuration of three clusters of indicators through which the implementation of fundamental rights can be measured and evaluated. These clusters correspond to the **commitments** and **efforts** of the duty-bearer (the state) and the **results** for rights-holders. These are respectively labelled as **structural**, **process** and **outcome** (S-P-O) indicators. Table 2 provides an overview of these indicators.







Table 2: Structural, process and outcome indicators

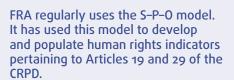
Indicator type	Key concerns	Focus	Description	Actors concerned
Structural	Legal, policy and institutional framework	Commitment	 Commitment to international human rights law Legislation in place Policies, strategies, action plans and guidelines adopted Institutional framework Existence of complaints and support mechanisms 	Duty- bearers
Process	Policy implementation and effectiveness of complaints and support mechanisms	Effort	 Budgetary allocations (Implementation of) policies, strategies, action plans, guidelines, etc. Effectiveness of complaints and support mechanisms 	Duty- bearers
Outcome	Situation on the ground – rights realised in practice	Results	Actual awareness of rightsActual impact of policies and other measuresActual occurrence of violations	Rights- holders

OHCHR stresses a few essential attributes for a well-functioning S–P–O framework: "the objective of using the conceptual framework is to encourage a practical, transparent and structured approach for a comprehensive translation of the human rights standards into concrete, well-defined, contextually meaningful indicators that help in the promotion and implementation of human rights".²⁰ However, it adds that, in the final analysis, "it may not matter if an indicator is identified as a process or outcome indicator so long as it captures relevant aspect(s) of an attribute of a right or the right in general".²¹

Lastly, it should be stressed that the S–P–O model does not imply any linear causality. For example, the framework should not be used to conclude or imply that a particular policy can, in itself, be responsible for a change in outcomes, or that a particular outcome can be attributed to an individual process. In reality, a statistically significant change in an outcome indicator is likely to be the result of a multitude of factors, of which an identifiable policy may or may not be one.

The following sections outline typical structures, processes and outcomes captured under the S–P–O indicators. They provide examples, drawing on the efforts of FRA to develop and populate human rights indicators to enable the assessment of the fulfilment of Article 19 ('living independently and being included in the community') and Article 29 ('participation in political and public life') of the CRPD.²²

The S-P-O model



A three-report series that FRA published in 2017 looks at different aspects of deinstitutionalisation and independent living for persons with disabilities. It explores the structures in place (*From* institutions to community living -Part I: Commitments and structures), the processes (From institutions to community living – Part II: Funding and budgeting) and the outcomes for persons with disabilities (*From* institutions to community living -Part III: Outcomes for persons with disabilities). FRA developed the indicator matrix that was used. This matrix was refined on the basis of input gathered during extensive consultation with relevant stakeholders.

The 2014 FRA report on the right to political participation for persons with disabilities analysed data on the situation of political participation of persons with disabilities. Data were







collected from across the (then) 28
EU Member States. FRA published an
update on developments in the situation
of the right to vote for persons deprived

of legal capacity in the EU in view of the

2019 European Parliament election.

The 2011 FRA symposium report <u>Using</u> <u>indicators to measure fundamental</u> <u>rights in the EU: Challenges and</u> <u>solutions</u> explores the potential of using indicators in measuring fundamental rights. It addresses five key areas of

work, including monitoring of CRPD implementation.

FRA has also used indicators in other areas. There are FRA documents concerning indicators on the rights of the child (Developing indicators for the protection, respect and promotion of the rights of the child in the European Union; this includes an annex containing checklists for indicator development) and in the area of Roma (Post-2020 indicator framework - Roma equality and inclusion concept paper for the workshop on future policies for Roma).

3.1. Structural indicators



Structural indicators focus on states' acceptance of and commitment to specific human rights obligations and aim to capture the more institutional aspects of fundamental rights commitments. Structural indicators reflect, for example, legislation and policies in place and the existence of institutional mechanisms.

Common structural indicators include:

- formal acceptance of standards (i.e. international human rights treaties ratified by the state);
- scope/content/time frame of strategies, policies and action plans;
- incorporation into national law;
- independence and mandate of monitoring;
- who can complain (standing).

Table 3 provides examples of structural indicators.

Table 3: Examples of structural indicators, drawing on FRA's human rights indicators on Articles 19 and 29 of the CRPD

Human rights standard	Structural indicators
Cross-cutting indicators	Does the state have mechanisms in place to ensure the consultation and involvement of persons with disabilities, irrespective of age and type of impairment, through organisations of persons with disabilities, in the: • design • development • implementation and monitoring • of laws and policies that affect them? Are there mandatory accessibility standards for government and local authority buildings?

Human rights standard	Structural indicators
Article 19 – Living independently and being included in the community	 Has the state committed to: shutting down long-stay residential institutions? stopping new admissions to long-stay residential institutions? not building new long-stay residential institutions?
	Is there a defined legal maximum number of users who can be accommodated in a particular type of institution? Does the limit vary according to age or type of impairment?
	Is there a legal provision for persons with disabilities, irrespective of age and type of impairment, to be able to choose:
	• the type of support service provided?
	the extent of support provided?the provider of the support service?changes in the support?
Article 29 – Participation in political and public life	Do national disability strategies include political participation? Does the state have legislation regulating how people living in long-term institutions may vote?

3.2. Process indicators

Process indicators focus on state **efforts** and initiatives to transform commitments into desired results. They aim to capture the state of implementation of policy instruments such as programmes and other state efforts to put structural level commitments into practice. Furthermore, process indicators relate to the existence of national-level policies concerned with the implementation of fundamental rights in the field; to the effectiveness of the complaints and monitoring mechanisms in place; and to the extent to which governance systems can deal with issues pertaining to fundamental rights.



Common process indicators include:

- budget allocations and trends over time;
- budgetary priorities and the beneficiaries of planned outcomes (e.g. who are open calls targeting?; are procedures explicitly, or in effect, excluding some potential beneficiaries?);

- the sustainability of the budget (sources);
- characteristics of complaints mechanisms judicial and quasijudicial (e.g. availability, accessibility, affordability);
- awareness-raising efforts (existence, content, scope, training).

Table 4 provides examples of process indicators.

Table 4: Examples of process indicators, drawing on FRA's human rights

Human rights standard	Process indicators
Cross-cutting indicators	Has there been a review of existing legislation to assess the EU Member State's compliance with Article X of the CRPD? Have existing legal acts been amended or has new legislation been adopted to ensure compliance with Article X of the CRPD? How many: • public officials • social workers • health workers • education workers • other service providers Have undergone training on the CRPD annually since 2010?
Article 19 – Living independently and being included in the community	How much money has been allocated, annually since 2010, to support persons with disabilities, irrespective of age or impairment, to move from an institutional setting to a living arrangement of their choice? Are the procedures for requesting the transfer of community support services accessible to all persons with disabilities, irrespective of age and impairment? Is assistance in completing administrative requirements available during the process of requesting the transferring of support?
Article 29 – Participation in political and public life	Is information on complaints mechanisms regarding political participation made accessible to persons with disabilities? Have national courts/non-judicial complaints mechanisms considered cases related to the right to political participation of persons with disabilities? Are there guidelines on how to make polling stations accessible?

3.3. Outcome indicators

At the level of outcomes, indicators relate to the situation on the ground. They focus on measuring the **results** of states' commitments and efforts pertaining to individuals' human rights situations (i.e. they measure how people experience the realisation of rights in practice).



OHCHR stresses that an outcome indicator "is often a slow moving indicator, less sensitive to capturing momentary changes than a process indicator". It also states that process and outcome indicators are not always exclusive, meaning that "a process indicator for one human right can be an outcome indicator in the context of another" ("For instance, the proportion of people covered by health insurance can be categorized as a process indicator for the right to health and as an outcome indicator for the right to social security").²³

Common outcome indicators include:

- number of people with disabilities who have access to personal support/assistive devices;
- number of people participating in (empowerment) trainings;
- perception of human rights protection;
- perception of human rights enjoyment;
- number of complaints received and their outcomes (proportion redressed);
- number of people aware of their rights and relevant complaints mechanisms (proportion of respondents reporting awareness of rights and relevant complaints mechanisms);
- number of people experiencing violations (proportion of respondents reporting experiencing violations);
- reporting rates (e.g. of discrimination, harassment, hate speech, hate crime).

Table 5 provides examples of outcome indicators.

Table 5: Examples of outcome indicators, drawing on FRA's human rights indicators on Articles 19 and 29 of the CRPD

Human rights standard	Outcome indicators
Cross-cutting	How many persons with disabilities have taken part in training and programmes aiming to increase their awareness of available support and services to live independently? Data should be disaggregated by type of impairment, level of support need, age and sex/gender.
Article 19 – Living independently and being included in the community	How many families of children with disabilities were granted, annually since 2010, adjustments to buildings, financial aid for adjustments to buildings or assistance for their place of residence? Data should be disaggregated by type of impairment, level of support need, age and sex/gender. What proportion, annually since 2010, of persons with disabilities live in: • privately owned or rented accommodation? • social housing? How do these proportions compare with those of the general population? Data should be disaggregated by type of impairment, level of support need, age and sex/gender.
Article 29 – Participation in political and public life	Are data available on the proportion of polling stations that are accessible to persons with disabilities? Were political party programmes provided in accessible formats during the most recent elections? Are persons with disabilities members of the current national parliament? Are data available on the number of members of municipal governments who have a disability?

PROMISING PRACTICE

Human rights-based approach to data collection

OHCHR developed guidelines on data collection and disaggregation to support the monitoring of progress towards achieving the goals of the 2030 Agenda for Sustainable Development. These guidelines aim to improve the quality, relevance and use of data and statistics consistent with international human rights norms and principles. The guidelines set out six principles of a human rights-based approach to data collection.

- Participation of relevant population groups in data collection exercises, including planning, data collection, dissemination and data analysis.
- Data disaggregation, which enables data users to compare population groups and to understand the situations of specific groups. Disaggregation requires the collection of data on relevant characteristics (sex, age, ethnicity, disability, sexual orientation or religion).
- Self-identification of populations of interest, giving individuals the option to disclose, or withhold, information about their personal characteristics.

- Transparency when collecting data, including the provision of clear, openly accessible information about data collectors' operations and the research design and methodology. Data collected by state agencies should be publicly accessible.
- Privacy, referring to individuals' responses and personal data being confidential and thus needing to be protected and kept private.
- Accountability, in terms of data collectors being accountable for upholding human rights in their operations. Data should be used to hold states and other actors to account on human rights issues.

For more information, see OHCHR (2016),
A human rights-based approach to data:
Leaving no one behind in the 2030 Agenda
for Sustainable Development.

4 Data sources for populating outcome indicators

Comprehensive mapping of available equality data is key to identifying relevant data sources and populating outcome indicators.²⁴ Efforts to foster linkages and combining different sources of data could also be beneficial.

Data should be drawn from standard data collection mechanisms (generic population data, which could be broken down/disaggregated by disability variables) and from targeted disability surveys and qualitative research.

What are equality data?

Equality data are crucial in monitoring how laws and policies are being implemented. They are indispensable in monitoring progress on the ground.

The European handbook
on equality data and the
Guidelines on improving the
collection and use of equality
data define equality data as
any piece of information useful
for the purposes of describing,
analysing, reasoning about and
decision making on the state of
equality. The information may
be quantitative or qualitative in
nature. It could include aggregate
data that reflect inequalities
or their causes or effects in
societies.

For more information, see: European Commission (2016), European handbook on equality data, Luxembourg, Publications Office. See also Compendium of practices for equality data collection, on the FRA website.

4.1. Data sources

Multiple data sources can serve as a basis for populating outcome indicators and, more generally, in the compilation of equality statistics. Data sources include the following.

- Population censuses.
- Administrative records and registers (e.g. number of services available, use of services).
- Surveys:
 - household and individual surveys at national and EU levels (Labour Force Survey, European Union Statistics on Income and Living Conditions survey, etc.);
 - victimisation surveys, such as the FRA <u>EU Survey on Immigrants</u> and Descendants of Immigrants;
 - attitudinal surveys and opinion polls (European Values Study surveys, Eurobarometer surveys, etc.).
- The results of discrimination testing through experimental field studies. This provides robust evidence of actual discrimination experiences. These experiences are applied to real-life settings, for example the labour or housing market, and indicate actual discriminatory practices. The experimental design of such studies enables causal conclusions to be drawn.²⁵
- Complaints-based data and case law (e.g. from judicial and quasijudicial bodies and data on outcomes, including on compensation offered/sanctions applied).
- Data collected by social partners (e.g. employers or trade unions).
- Data collected by public or private service providers in the area of disability.
- Data collected from diversity monitoring by employers and service providers.
- Data used to train algorithms in the context of artificial intelligence and machine learning.
- Reports and information from non-governmental organisations and other civil actors.
- Academic research.²⁶

At state level, these data sources are under the responsibilities of a number of different public bodies, for example national statistical institutes, bodies tasked with social protection and social security, or municipal-level service providers.

Furthermore, data collection efforts at national level are based on different methodological approaches and definitions of disability. While official statistics cover people with long-standing conditions or diseases, the social security system uses disability certificates as indicators of disability. Some surveys, such as the European Health Interview Survey, rely on self-perception. Therefore, many different definitions are used (e.g. of 'disability') and many different methodologies are employed (e.g. differences between questions asked in surveys). Thus, it is important to be aware that data, even though they may relate to the same subject, may not always be comparable either within or between countries.

PROMISING PRACTICE

Global Activity Limitation Indicator

Use of a uniform definition or identifier for persons with disabilities across data collection efforts and time is recommended. Otherwise, one cannot compare results and outcomes across time, fields or data from different sources.

The European Statistical System uses the Global Activity Limitation Indicator (GALI) to measure disability. GALI is the measure underlying the European 'healthy life years' indicator.

GALI asks individuals to rate, for at least the past six months, the extent to which they have been limited in normal activities due to a health problem ("For at least the past six months, to what extent have you been limited because of a health problem in activities people usually do? Would you say you have been (1) Severely limited, (2) Limited but not severely, (3) Not limited at all or (4) Prefer not to say").

Since 2015, European surveys such as EU Statistics on Income and Living Conditions surveys, the Survey of Health, Ageing and Retirement in Europe and the European Health Interview Survey have used this instrument to capture prevalence of activity limitation. Many national statistical systems have also used it. It is widely accepted and used to compare population health across countries. However, there are also concerns with regard to its validity and reliability.

See Van Oyen, H., Bogaert, P., Yokota, R. T. C. and Berger, N. (2018), Measuring disability: A systematic review of the validity and reliability of the Global Activity Limitations Indicator (GALI), Archives of Public Health, Vol. 76, No. 25; and Berger, N., Van Oyen, H., Cambois, E., Fouweather, T., Jagger, C, Nusselder, W. and Robine, J.-M. (2015), Assessing the validity of the Global Activity Limitation Indicator in fourteen European countries, BMC Medical Research Methodology, Vol. 15, No. 1.

4.2. EU level data sources

There are also a number of sources at European level that provide data on persons with disabilities. These are from Eurostat and other sources. For example:

- European Working Conditions Surveys;
- Survey of Health, Ageing and Retirement in Europe;
- European Social Survey;
- European Quality of Life Survey;
- European Union Statistics on Income and Living Conditions surveys;
- EU Labour Force Survey and its ad hoc module 'Employment of disabled people';
- European Health Interview Survey;
- European Health and Social Integration Survey;
- Eurobarometer surveys.

International bodies could also serve as a source of data for populating outcome indicators. Sources include the <u>Global Health Observatory</u> of the World Health Organization, the <u>Centre of Excellence on Data for Children with Disabilities</u> of the United Nations Children's Fund (UNICEF), the World Bank <u>disability inclusion web page</u> and the International Labour Organization <u>disability and work web page</u>.

PROMISING PRACTICE

Seen, counted, included: Using data to shed light on the well-being of children with disabilities

UNICEF's global report on children with disabilities, published in 2022, includes the first-ever global and regional estimates of numbers of children with disabilities. It covers more than 60 indicators of child wellbeing, including health, education, access to water and sanitation, and protection from violence and exploitation. The data

were collected using three instruments: the UNICEF/Washington Group Child Functioning Module, the Washington Group Short Set on Functioning and the Global Activity Limitation Indicator.

Source: UNICEF (2022), Seen, counted, included: Using data to shed light on the well-being of children with disabilities.

4.3. Measuring initiatives

Data and indicators for monitoring the implementation of the CRPD should address and measure both specific disability initiatives and broader national initiatives and how they affect persons with disabilities, in line with recommendations of the CRPD Committee.²⁷ For this, it is also important to gather data periodically and comparatively across time. It is important for variables and indicators to be updated periodically to reflect any changes.

Mainstreaming disability in data collection has the advantage of enabling disaggregation by existing indicators. This reduces the cost of collecting disability data by adding a disability module into existing tools. It also signals that the considerations of persons with disabilities are a core policy issue.²⁸

At times, however, a specific disability survey is appropriate, for instance when governments and public authorities want to obtain information that goes beyond what existing instruments can offer. Finally, some indicators can be expected to change slowly, and therefore their collection is not required as regularly as that of some core economic or social inclusion indicators.²⁹

Hard-to-reach groups

Data on persons with disabilities are generally lacking. Some groups are left out even more and not captured by any data collection mechanisms, causing their experiences to remain hidden to the public eye. These are, for example, people living in institutions (small or big, public or private) or people with severe forms of impairment.

Data from the European social surveys, and most national data collection efforts, cover only persons living in private households. These data therefore do not include persons living in group settings such as institutions, group homes and residential family settings.

This creates a major gap in the available statistical data. Any interpretation of the data must acknowledge this.

5 Monitoring CRPD implementation across the European Union –national practice examples

Paragraph 2:

"[The CRPD] is one of the human rights treaties that expressly requests States parties to establish a framework for monitoring its provisions at the national level. The Convention goes even further [...] in requiring that, in establishing a monitoring framework, States parties take into account the principles relating to the status of national institutions for the protection and promotion of human rights (the Paris Principles) and that members of civil society, in particular persons with disabilities and their representative organizations, fully participate in the monitoring process."

+

Source: UN Committee on the Rights of Persons with Disabilities (2016), Rules of Procedure of the Committee on the Rights of Persons with Disabilities-Annex-Guidelines on independent monitoring frameworks and their participation in the work of the Committee on the Rights of Persons with **Disabilities**, IV. 'Monitoring implementation of the Convention at the national level', paragraph 2.

Member States have different approaches towards designating or establishing a national Article 33 (2) framework. This reflects the margin of appreciation the Convention gives parties to the treaty.

The CRPD establishes two criteria. First, the framework must include an independent mechanism, in accordance with the Paris Principles. The second, more implicit, criterion is that the national framework must be composed so as to deliver on its tasks to promote, protect and monitor the implementation of the Convention.³⁰

All EU Member States, and Albania and North Macedonia, have designated or established independent national monitoring frameworks. The great majority have appointed national human rights bodies, including national human rights institutions, equality bodies and/or ombudsperson organisations, to act as Article 33 (2) frameworks. A few states have given the task to other existing bodies, while others have created new entities to fulfil this role. The EU Framework maintains an annually updated table of national monitoring frameworks on its <u>website</u>.

This section presents information about national practices from more than half of the Article 33 (2) frameworks in the EU Member States gathered by FRA with the support of the <u>Working Group on the Convention on Rights of Persons with Disabilities</u> of ENNHRI. Article 33 (2) bodies from the following EU countries did not provide information: Belgium, Croatia, Cyprus, Finland, Germany, Greece, Hungary, Romania and Slovakia. Only a few of the national monitoring frameworks reported that they use indicators in their work. Moreover, the national approaches vary widely across countries, in terms of both their scope and the framework applied.

Bulgaria and Czechia use the OHCHR human rights indicators model. FRA, as part of its capacity-building work, facilitated technical workshops in Sofia (in February 2020) and in Prague (in September 2022). These workshops provided information and informal technical support for developing indicators for monitoring CRPD implementation.

In Bulgaria, there are indicators for Article 9, specifically on monitoring the accessibility of facilities (Article 9, paragraph 1 (a): "Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces").

The Czech Public Defender of Rights has produced two sets of indicators, covering a total of six articles of the CRPD (Articles 5, 9, 12, 19, 24 and 27). **Draft indicators for Articles 5, 12, 19 and 27** were made available (in Czech) for the purposes of a seminar on CRPD indicators held in September 2021.

The German Institute for Human Rights, the German Article 33 (2) body, monitors federal-level action plans, equality laws, voting rights, coalition agreements and violence in inpatient institutions.³¹ Many of the indicators used aim to trigger data collection rather than evaluation of outcomes. This is due to a lack of disability-specific data.

In Denmark and the Netherlands, indicators are largely 'outcome' focused and are used to compare the situation of persons with and without disabilities.

The Danish Institute for Human Rights' 'Gold Indicators' are a set of 10 statistical outcome indicators covering key thematic areas.³² All indicators are disaggregated by sex, ethnicity, age, type of disability and degree of disability, thereby highlighting the intersections between disability and these categories.³³ The project builds mainly on the periodic Survey of Health, Impairment and Living Conditions, which the Danish Center for Social Science Research and Statistics Denmark conduct every four years. Indicators are available in Danish on the **Handicapbarometer website** for Articles 5, 9, 15–17, 19, 24, 25 and 27–29.³⁴

The Netherlands Institute for Human Rights also uses quantitative indicators to monitor the extent to which persons with disabilities are able to participate in society. So far, the institute has developed indicators relating to living independently and being included in the community (Article 19), education (Article 24) and work and employment (Article 27). The selection of these three articles was based largely on the availability of data. Measurements to populate the indicators have been conducted for 2012, 2016 and 2020.³⁵

The right to political participation (Article 29) has been a focus for the Polish Article 33 (2) framework. Monitoring activities are carried out in Poland during each general election (they did not take place during the 2020 presidential election due to the coronavirus disease 2019 pandemic).³⁶

The Estonian Article 33 (2) framework has also focused on the right to political participation (Article 29). The office of the Chancellor of Justice, the CRPD monitoring body in Estonia, periodically assesses the accessibility of polling stations and highlights shortcomings to the authorities.³⁷

Some Article 33 (2) frameworks report that they intend to develop indicators in the future. For example, the Italian monitoring framework has defined a set of indicators in collaboration with the Italian National Institute of Statistics. These indicators relate to EU funds. They include:

- percentage of employed people aged 15-64 years with severe limitations;
- percentage of people aged 15–64 years with severe limitations participating in social activities;
- percentage of public transport users among people aged 15–64 years with severe limitations;
- percentage of daily users of public transport among people aged
 15-64 years with severe limitations.

The Irish Human Rights and Equality Commission (IHREC) does not currently use indicators to measure the implementation of the CRPD. However, activities involving the use of indicators are laid out in the Assisted Decision-Making (Capacity) (Amendment) Bill 2021, which is pending enactment.

Ireland ratified the CRPD in 2018, and since then IHREC has acted as the designate independent monitoring mechanism. This role has yet to be given a statutory basis by way of an amendment to the IHREC Act 2014. However, this is set to be provided for in the Assisted Decision-Making (Capacity) (Amendment) Bill 2021. The Disability (Miscellaneous Provisions) Bill 2016 sought to provide this statutory basis, but it lapsed upon the last dissolution of parliament in 2020.

The Assisted Decision-Making (Capacity) (Amendment) Bill 2021 introduces amendments to the National Disability Authority Act. It provides for a new statutory function of the National Disability Authority to assist IHREC with its monitoring role, including through the development and provision of statistical information.³⁸ That said, the National Disability Authority has already developed and published a set of indicators to monitor implementation of Ireland's current policy framework for persons with disabilities – the *National Disability Inclusion Strategy (2017–2021).*³⁹ Although the strategy is not specific to Ireland's implementation of the CRPD, it covers relevant thematic areas, such as education; employment; health and well-being; person-centred disability services; housing; transportation; accessibility; and independent living.⁴⁰

The National Disability Authority has also published indicators for monitoring progress under the *Comprehensive Employment Strategy* for People with Disabilities 2015–2024,⁴¹ which sets out Ireland's strategy for improving the employment situation of disabled people.

Other frameworks use indicators indirectly, making use of data – statistical and other – to inform their monitoring activities. For example, in addition to large reports on various topics, the Latvian Ombudsman conducts periodical surveys measuring societal attitudes towards the rights of persons with disabilities. It also researches one CRPD article per year in depth. In 2022, the focus is on Article 9 (accessibility).

Similarly, in Austria, the CRPD monitoring committee organises annual public meetings gathering input on specific CRPD articles and other relevant topics.⁴²

The Portuguese Disability and Human Rights Observatory publishes an annual report on human rights indicators in relation to persons with disabilities. This assesses the implementation of the CRPD in Portugal through the analysis of secondary sources.⁴³

6 Challenges and ways forward

6.1. Challenges in developing and/or using indicators

National frameworks have reported challenges in relation to both the difficulties inherent in collecting disability information and their capacity to do so. The challenges that some national frameworks experience in relation to developing and/or using indicators include the following.

- Lack of available disability-specific data at national level. This leads to the use of indicators aiming to collect data rather than to evaluate outcomes. In addition, a lack of access to data from existing surveys can result in populating indicators with data from alternative sources, such as scientific research outputs. This can lead to challenges in data consistency, which limit the ability of frameworks to describe developments over time.
- Inaccurate interpretation of the data protection frameworks pertaining to collection and processing of personal data such as data concerning health.⁴⁴
- Different definitions of disability used by various organisations carrying out monitoring. This could be overcome by using a national centralised statistical platform using a common definition of disability or applying the CRPD definition.
- Difficulty in precisely delimiting specific groups of persons
 with disabilities so that these statistical groups are not too
 narrow (and thus exclude certain individuals) or too broad (and
 thus unnecessarily expand the groups, rendering meaningful
 comparisons difficult).
- Limitations caused by the general nature of the information collected based on indicators. Having a general indication is often interesting. However, this limits insight into the specific situations and causes of progress or lack thereof. It also makes it difficult to develop specific recommendations.
- Methodological difficulties faced when defining indicators and analysing the results.

- The time and financial resources available for developing indicators for all articles of the CRPD. A lack of such resources leads, or could lead, to other activities being deprioritised.
- Lack of sound legal and sustainable financial footing as an independent and autonomous entity.

6.2. Working methods to use and/or develop indicators

National frameworks have developed a number of working methods in relation to using and/or developing indicators. It may be useful for other frameworks to consider these. Such working methods include the following.

- Building on previous work that focused on specific CRPD articles and then looking at all articles when starting to develop indicators.
- Using what is available in terms of indicators and areas for which data are available, and later focusing on those for which no data are available (yet).
- Using indicators to help specify the need for additional information, statistics and research. Examples include when the measurements make clear that, for specific groups (e.g. persons with severe intellectual disabilities) or for specific areas, data are limited and additional research must be carried out to obtain more information on the rights of persons with disabilities.
- Using the information collected to highlight specific concerns and support activities related to Article 33 (2), to promote and monitor the implementation of the CRPD.
- Developing indicators to enable establishing cooperation with bodies responsible for data collection at national level (e.g. national statistical offices, national health statistics bodies, ministries).
- Granting an important role to cooperation with the greatest practicable quantity and diversity of local actors, both from civil society and from companies and local government, and with relevant actors at international level.
- Developing indicators in close collaboration with civil society representatives, researchers and relevant authorities. This enables the development of indicators with direct relevance to the individuals and groups in society that are most affected by the areas of life being monitored.
- Gathering available knowledge about how to best proceed with the indicators (e.g. through a specialised seminar).

References

- Degener, T. (2016), **Disability in a Human Rights Context**.
- European Commission (2016), <u>European handbook on equality</u> <u>data</u>, Luxembourg, Publications Office of the European Union (Publications Office).
- European Commission (2021), <u>Union of equality: Strategy for the rights of persons with disabilities 2021–2030</u>, COM(2021) 101 final, Brussels, 3 March 2021.
- European Commission, High Level Group on Non-discrimination, Equality and Diversity, Subgroup on Equality Data (2018),
 <u>Guidelines on improving the collection and use of equality data</u>, Brussels, European Commission.
- European Commission, High Level Group on Non-discrimination, Equality and Diversity, Subgroup on Equality Data (2021), <u>Guidance</u> <u>note on the collection and use of equality data based on racial or</u> <u>ethnic origin</u>, Brussels, European Commission.
- FRA (2014), The right to political participation for persons with disabilities: Human rights indicators, Luxembourg, Publications Office.
- FRA (2015), Implementing the UN CRPD: An overview of legal reforms in EU Member States, FRA Focus 05/2015, Vienna, FRA.
- FRA (2016), <u>Opinion of the European Union Agency for</u>
 <u>Fundamental Rights concerning requirements under Article 33 (2)</u>
 <u>of the UN Convention on the Rights of Persons with Disabilities</u>
 <u>within the EU context</u>, FRA Opinion 3/2016 [CRPD], Vienna, FRA.
- Ireland (2021a), <u>Assisted Decision-Making (Capacity)</u>
 (Amendment) Bill 2021: Draft general scheme and heads of bill,
 22 November 2021.
- Ireland (2021b), National Disability Inclusion Strategy (2017–2021).
- Ireland, National Disability Authority (2018), <u>An indicator set to</u> monitor the National Disability Inclusion Strategy 2017–2021.
- Ireland, National Disability Authority (2020), <u>Indicators for</u> monitoring progress under the Comprehensive Employment Strategy for Persons with Disabilities 2015–2024.
- Netherlands Institute for Human Rights (College voor de Rechten van de Mens) (2022), Understanding inclusion III: People with disabilities still at a disadvantage (Inzicht in inclusie III: Mensen met een beperking nog steeds op achterstand), Utrecht, Netherlands Institute for Human Rights.
- OHCHR (2012), Human rights indicators: A guide to measurement and implementation, HR/PUB/12/5, New York and Geneva, United Nations.

- Poland, Commissioner for Human Rights (Rzecznika praw obywatelskich) (2019), Dostosowanie lokali obwodowych komisji wyborczych do potrzeb wyborców z niepełnosprawnościami, Warsaw, Commissioner for Human Rights.
- UN Committee on the Rights of Persons with Disabilities (2016), Rules of Procedure of the Committee on the Rights of Persons with Disabilities-Annex-Guidelines on independent monitoring frameworks and their participation in the work of the Committee on the Rights of Persons with Disabilities.
- United Nations Office of the High Commissioner for Human Rights (2008), Report on indicators for promoting and monitoring the implementation of human rights.

Suggestions for further reading

- Danish Institute for Human Rights (DIHR) (2019), <u>Indicators and</u> <u>data for human rights and sustainable development: A practical approach to leaving no one behind</u>, Copenhagen, DIHR.
- Danish Institute for Human Rights (DIHR) and the Global Alliance of National Human Rights Institutions (2022), *Indicators and data for human rights and sustainable development: A guide for national human rights institutions*, Copenhagen, DIHR.
- European Commission (2021), <u>European comparative data on</u>
 <u>Europe 2020 and persons with disabilities</u>, Brussels, European
 Commission.
- European Commission (2021), <u>Union of equality: Strategy for the rights of persons with disabilities 2021–2030</u>, COM(2021) 101 final, Brussels, 3 March 2021.
- European Commission, Academic Network of European Disability
 Experts (2009), Monitoring the implementation of the UN
 Convention on the Rights of Persons with Disabilities in Europe:
 Principles for the identification and use of indicators, Human
 European Consultancy and University of Leeds, May 2009.
- European Commission, High Level Group on Non-discrimination, Equality and Diversity, Subgroup on Equality Data (2018),
 Guidelines on improving the collection and use of equality data, Brussels, European Commission.
- Eurostat (undated), 'Disability statistics introduced'.
- FRA (European Union Agency for Fundamental Rights) (2010), Developing indicators for the protection, respect and promotion of the rights of the child in the European Union, Vienna, FRA (see the annex "Check-lists for indicator development").
- FRA (European Union Agency for Fundamental Rights) (2011), <u>Using</u>
 indicators to measure fundamental rights in the EU: Challenges
 and solutions, FRA Symposium Report, Vienna, FRA.
- FRA (European Union Agency for Fundamental Rights) (2014), <u>The right to political participation for persons with disabilities: Human rights indicators</u>, Luxembourg, Publications Office of the European Union (Publications Office).
- FRA (European Union Agency for Fundamental Rights) (2015),
 Human rights indicators on Article 19 of the CRPD, Vienna, FRA.
- FRA (European Union Agency for Fundamental Rights) (2016),
 Opinion of the European Union Agency for Fundamental Rights
 concerning requirements under Article 33 (2) of the UN Convention
 on the Rights of Persons with Disabilities within the EU context,
 FRA Opinion 3/2016, 13 May 2016.

- FRA (European Union Agency for Fundamental Rights) (2017),
 From institutions to community living Part I: Commitments and structures, Luxembourg, Publications Office.
- FRA (European Union Agency for Fundamental Rights) (2017), <u>From institutions to community living Part II: Funding and budgeting</u>, Luxembourg, Publications Office.
- FRA (European Union Agency for Fundamental Rights) (2017), <u>From institutions to community living Part III: Outcomes for persons with disabilities</u>, Luxembourg, Publications Office.
- FRA (European Union Agency for Fundamental Rights) (2018),
 From institutions to community living: Development of statistical outcome indicators, Vienna, FRA.
- OHCHR (2012), <u>Human rights indicators: A guide to measurement</u> and implementation, HR/PUB/12/, UN.
- OHCHR (2018), <u>A human rights based approach to data Leaving</u>
 <u>no one behind in the 2030 Agenda for Sustainable Development</u>,
 UN.
- UN Committee on the Rights of Persons with Disabilities (2016),
 Rules of Procedure of the Committee on the Rights of Persons with Disabilities-Annex-Guidelines on independent monitoring frameworks and their participation in the work of the Committee on the Rights of Persons with Disabilities
- UN (undated), '<u>United Nations Disability Statistics Programme</u>'.
- UN Department of Economic and Social Affairs (2015), <u>Disability</u> indicators for the SDGs.
- UN Department of Economic and Social Affairs (2015),
 Operationalizing the 2030 agenda: Ways forward to improve monitoring and evaluation of disability inclusion.
- UN Department of Economic and Social Affairs (2018), <u>Disability</u> and development report Realizing the Sustainable Development Goals by, for and with persons with disabilities, New York, UN.
- World Health Organization (WHO) (2015), WHO global disability action plan 2014–2021, WHO.
- World Health Organization (WHO) and World Bank (2011), World report on disability, WHO.
- World Health Organization (WHO) and World Bank (2017), <u>Model</u>
 Disability Survey (MDS) Survey manual, WHO.

Endnotes

- 1 See FRA (2015).
- 2 United Nations (undated), paras 4, 34.
- 3 *Ibid.*, para. 39 (c).
- 4 See Degener (2016).
- 5 United Nations (undated), para. 39 (d).
- 6 Ibid., para. 13.
- 7 OHCHR (2012).
- 8 Ibid., p. 17.
- 9 United Nations (undated), para. 38.
- 10 For more information, see European Commission (2016), pp. 15–19.
- 11 United Nations (undated), paras 35, 37.
- European Commission, High Level Group on Non-discrimination, Equality and Diversity, Subgroup on Equality Data (2018), pp. 9–11.
- 13 European Commission (2021), pp. 31–32.
- 14 Ibid.
- 15 For the European Semester framework and access to European Semester documents for all EU Member States, see 'The European Semester'.
- 16 Regulation EU 2021/1060 of the European Parliament and of the Council of 24 June 2021 laying down common provisions on the European Regional Development Fund, the European Social Fund Plus, the Cohesion Fund, the Just Transition Fund and the European Maritime, Fisheries and Aquaculture Fund and financial rules for those and for the Asylum, Migration and Integration Fund, the Internal Security Fund and the Instrument for Financial Support for Border Management and Visa Policy, OJ 2021 L 231 (Common Provisions Regulation 2021–2027).
- 17 *Ibid.*, Annex III, p. 322.
- Office of the United Nations High Commissioner for Human Rights, **Report on indicators for promoting and monitoring the implementation of human rights**, p. 4.
- 19 OHCHR (2012), p. 16.
- 20 Ibid., p. 44.
- 21 Ibid., p. 86.
- 22 See 'Human rights indicators on Article 19 CRPD'; and FRA (2014).
- 23 See OHCHR (2012), Chapter IV.
- 24 See European Commission, High Level Group on Non-discrimination, Equality and Diversity, Subgroup on Equality Data (2018), specifically Guideline 1 'Map existing sources of equality data and identify gaps', pp. 13–14.
- 25 For more information, see European Commission (2016), p. 34.
- 26 European Commission, High Level Group on Non-discrimination, Equality and Diversity, Subgroup on Equality Data (2018), Principle 6, pp. 4, 14.
- 27 United Nations (undated), para. 39 (c).
- 28 Ibid.

- 29 Ibid.
- 30 For more information, see FRA (2016), p. 12.
- These action plans are available on the **website of the German Institute for Human Rights** (in German).
- 32 'The gold indicators: Measuring 10 key thematic areas to improve the situation of persons with disabilities'.
- 33 More information is available on the Danish Institute for Human Rights web page on the disability index.
- 34 For more information, see the Handicapbarometer website.
- For the latest report, see Netherlands Institute for Human Rights (*College voor de Rechten van de Mens*) (2022), Measurements I and II.
- For the latest report (in Polish), see Poland, Commissioner for Human Rights (*Rzecznika praw obywatelskich*) (2019).
- 37 See the <u>annual reports</u> and the <u>database of opinions</u> of the Chancellor of Justice.
- 38 Ireland (2021a), Head 81.
- 39 Ireland (2021b).
- 40 Ireland, National Disability Authority (2018).
- 41 Ireland, National Disability Authority (2020).
- 42 For more information, see the <u>list of public meetings on the website</u> of the CRPD monitoring committee.
- 43 More information is available on the **2019** and **2020** Disability and Human Rights Observatory web pages on human rights indicators regarding persons with disabilities in Portugal.
- The European Commission has published **general guidance**. See also European Commission, High Level Group on Non-discrimination, Equality and Diversity, Subgroup on Equality Data (2018), **Guidelines on improving the collection and use of equality data**, pp. 9–11.

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Promoting and protecting your fundamental rights across the EU —

This guide helps independent national monitoring frameworks to fulfil their monitoring responsibility set out in Article 33 of the Convention on the Rights of Persons with Disabilities (CRPD) (hereinafter 'the Convention'). It focuses on the use of indicators and its objective is to support national monitoring frameworks in designing or improving indicators for assessing progress of CRPD implementation at national level.







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