

**POLICY REPORT**

Equality Data Initiative

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**ETHNIC ORIGIN AND  
DISABILITY DATA  
COLLECTION IN EUROPE:  
MEASURING INEQUALITY -  
COMBATING DISCRIMINATION**

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**OPEN SOCIETY  
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## Glossary

**Equality data:** all types of disaggregated data used to assess the comparative situation of a specific group at risk of discrimination. Equality data can be collected based on different methodologies (third-party identification, self-identification, auto-hetero perception, objective criteria) and using different sources (public censuses, administrative registers, surveys, etc.).

**Third-party identification:** attribution of personal characteristics to the data subject by a third person based their (external) perception or evaluation.

**Self-identification:** attribution of personal characteristics to the data subject by themselves based on their own (internal) perception of their identity.

**Proxies / objective criteria:** criteria that do not directly identify sensitive data but are being used to indirectly provide indications considered as objective (nationality, country of birth, etc.).

**Auto-hetero perception:** evaluation or estimation by the data subjects of the personal characteristics that they believe third persons (the majority) are likely to attribute to them.

**“Where there’s a will, there’s a way.”**

*-Old English proverb*

## Executive summary

The term “equality data” in this report denotes all types of disaggregated data used to assess the comparative situation of a specific group at risk of discrimination collected using various techniques, including public statistics, administrative registers, surveys, internal monitoring by enterprises or public administrations, data from the judicial system, and data on complaints to equality bodies.<sup>1</sup>

European antidiscrimination law cannot be effectively implemented without collecting equality data because data are essential to measure inequalities, to target social policies and monitor implementation as well as to design remedies including positive action measures. Nobody in Europe seems to disagree with this axiom, and this logic is not questioned where gender and age are concerned. Gender and age data are readily available for all sorts of purposes. For instance, the 2012 Commission proposal aiming to improve the gender balance among non-executive directors of companies listed on stock exchanges<sup>2</sup> is based on data about the lack of women in management positions, while legal challenges, whether before national courts or reaching the European level, are often based on gender and age data.

However, not all grounds protected under European antidiscrimination law benefit from such data. It is mandatory to collect disability data both at the national and the EU level following the ratification by both Member States and the European Union itself of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).<sup>3</sup> Despite this, disability categories are often medicalized and it has not yet been established which data sets can best be used to indicate inequalities and inform policy making. In contrast, it is often claimed that data are not collected on the basis of ethnic origin, while data revealing ethnic origin are available not on the basis of self-identification but through proxies, such as migration status and language proficiency. On the one hand, due to the lack of (proper) data, measures countering discrimination on the grounds of disability and ethnic origin must be based on something other than statistical facts. On the other hand, the lack of data on these grounds deprives people with disabilities or an ethnic minority background of the tools needed to challenge discrimination. It is doubtful whether the European Union can measure the progress made by the implementation of the antidiscrimination directives, while it appears next to impossible to gauge the impact of EU-funded projects targeting disability and ethnic minority communities.

What comes automatically in the case of gender and age does not seem at all straightforward in the case of disability and ethnic origin. The logical question is therefore: do people who live with disabilities or come from an ethnic minority background suffer disadvantages on

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1 Open Society Foundations 2014, *Equality Data Initiative Background Paper*.

2 European Commission, 2012, Proposal for a directive of the European Parliament and of the Council on improving the gender balance among non-executive directors of companies listed on stock exchanges and related measures, COM (2012) 614.

3 See Article 31 of the CRPD.

account of data shortages? Is there a way and is there a duty to remedy such disadvantages? The first part of the question has an easy answer — at least as far as ethnic origin is concerned – because ethnic data are collected in various parts of the world from Australia through the United Kingdom to the United States. Given that the debate on disability is more recent, best practice examples are fewer and further between. The second part of the question can be answered in the affirmative on the basis of a careful analysis of Member States’ duties under European antidiscrimination law and the relevant international treaties.

Equality arguments are countered by data protection duties. There is a commonly held view in Europe that the collection of disability and ethnic data is categorically prohibited. This is not true under the present European data protection regime, while collecting data may become easier under the emerging new rules. The European Union’s Data Protection Directive permits the collection of sensitive data for a handful of purposes, as long as safeguards – what this report terms “binding core principles” — are observed.<sup>4</sup> National legislations should operate under these complementary tenets. Still, Bulgaria, France, Germany, Hungary, Ireland, Romania, and Sweden as well as much of continental Europe are locked in a self-inflicted *equality data paralysis*. Factors such as the lack of definition of disability, race and ethnic origin in European law, as well as the lack of legislation or case law resolving real or assumed conflicts between equality data collection needs and data protection duties, add to this phenomenon.

While materials have been produced in abundance on the theoretical underpinnings as well as on the actual practice of data collection, continental Europeans seem to be at a loss. There is also an alarming disconnect between theory and practice, while actual data collection practices often breach the binding core principles.

Public debate pays no particular regard to disability data, while ethnic data are politicized, fundamentally because the categories used are contingent upon European societies’ relationship to their multicultural citizenry. Among the general population, there is a *broad degree of willingness* to provide personal information as part of a census on an anonymous basis to combat discrimination, and *relatively little resistance*. Three out of four European Union citizens would be willing to provide personal information about their ethnic origin (75 percent) and 71 percent would be willing to do so concerning their health situation.<sup>5</sup>

A need for equality data has been generated by the adoption of the antidiscrimination directives. As we move from standard setting to implementation, even the European Commission views data collection as central to any development in this field.<sup>6</sup> The binding core principles of equality data collection that are endorsed by disability and ethnic minority communities strike a balance between the right to privacy and other human rights standards. It is now time to apply them for the purposes of fighting discrimination and ensuring equality.

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4 See Article 8.2 of Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data.

5 Special Eurobarometer 263 Discrimination in the European Union, European Commission, 2007, p. 28.

6 Joint Report on the application of Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin (‘Racial Equality Directive’) and of Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation (‘Employment Equality Directive’), COM(2014) 2, 17 January 2014, p. 5.

Some equality data are collected by statisticians but remain patchy and incoherent. International treaty monitoring bodies have called for precise and comprehensive equality data to assess the impact of state policies. Official ethnic data show discrepancies with unofficial ethnic data, while due to diverse categorization, data on disability — particularly on milder forms of disability — greatly vary across Member States.

This report seeks to bridge the gap between theory and practice in relation to the collection of disability and ethnic origin data. These two grounds of discrimination are of particular relevance as they are the only grounds covered by law in all EU Member States outside the field of employment for which data are not readily available: ethnic origin through the Racial Equality Directive and disability through the CRPD, which has been ratified by Member States as well as the European Union. This report synthesizes desk research carried out in seven Member States in the first half of 2013, while also focusing on the deliberations and conclusions of national stakeholder meetings held in these countries between March and August 2014.

The thematic focus is on public education — except for in France where, given the national context, public employment is covered. The report assesses the relevant legal framework and practice at the national and EU levels. It establishes the binding core principles of equality data collection and proposes a framework for ethnic categories and question sets. It calls attention to criticism voiced by disability communities regarding the disability questions developed after the adoption of the CRPD and recommends the use of categories of special educational needs (SEN) in the field of education in order to demedicalize disability. Finally, it puts forward recommendations for action at both the national and EU levels in order to achieve effective change on the ground.

The present data protection framework governing equality data is one of “prohibition with exceptions.” While some exemptions are quite precise and cover specific situations, others allow a margin of appreciation on the side of the legislator or data collectors. These provisions are generally based on Article 8.4 of the Data Protection Directive 95/46/EC that permits the processing of sensitive personal data where the protection of a “substantial public interest” is at stake. Tackling discrimination and ensuring substantive equality should clearly be covered by the term “substantial public interest.”

The main methods used in the seven countries to identify the personal characteristics of data subjects are (i) self-identification; (ii) third-party identification; and (iii) proxies (i.e., criteria considered to be objective by the majority population). Ethnic data are collected through proxies or third-party identification, which is often ineffective or unlawful while perpetuating stereotypes and discrimination. Such practices disregard the binding core principles identified as a result of this study and including self-identification of the data subject and consent based, voluntary and anonymized data collection. Third-party identification as well as the use of proxies that reveal ethnic origin need to be brought into line with the relevant data protection rules.

Except in Sweden, disability data are officially collected in the field of public education. There is no clear demand from stakeholders to stop third-party identification of disability in education

where it is conducted by expert commissions prior to enrollment or during schooling. Following the adoption of the CRPD, for the purposes of collecting census and survey data, the Budapest Initiative in cooperation with the Washington Group for Disability Statistics<sup>7</sup> has developed self-identification based disability identification questions (short and long sets of questions) compatible with the International Classification of Functioning, Disability and Health (ICF).<sup>8</sup> In view of the ratification of the CRPD by the EU, these question sets need to be validated at the EU and national levels with the involvement of disability organizations. Irish and German NGO stakeholders indicate the need to collect data in the field of education on the basis of special educational needs and with a view to measuring gaps in achievement, while Swedish and Irish disability NGOs urge that the ICF-compatible question sets be demedicalized in consultation with disability communities.

The time is ripe for the development of the ethnic origin categories and question sets at the EU as well as national levels. In the framework of a European Social Survey (ESS) related pilot project, new sets of questions relating to ethnic origin have been tested. The European Union Agency for Fundamental Rights (the Fundamental Rights Agency, FRA) on the other hand, has collected data based on its own categories that depict broad geographic origin. In addition, both the FRA and the ESS ask open questions on ethnic origin and religion, while the FRA has also collected data on discrimination experiences. However, disability and ethnic minority communities have not been consulted or indeed been involved in these processes. The need to consult communities was voiced during the national stakeholder meetings. Communities are in favor of collecting data on discrimination experiences in order to buttress data on inequalities.

In the context of diverse degrees of wariness among — especially ethnic minority — communities consulted during the national stakeholder meetings, the basic demand regarding data protection is to ensure that equality data are not abused. There seems to be little awareness at the community level of the proper interpretation of present – and even less of draft – data protection rules. However, it is important to note that except for the few NGO stakeholders that categorically oppose (ethnic) data collection, the overwhelming majority embrace data protection safeguards, and if anything, they call for more effective guarantees. As the FRA and ESS surveys show, equality data are already being collected under the present data protection regime, but the refusal of “data subjects” to respond is dependent on the trust and historical experiences of the different ethnic minority communities.

The bottom line is that even if anonymized or pseudonymized, data will necessarily be collected from individuals who need to consent to data collection on the basis of information regarding the purpose of the exercise, but who cannot afterwards control the use of the data so rendered. Clearly, the stronger the safeguards and the more reliable the methodologies, the greater

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7 The Washington Group on Disability Statistics was formed as a result of the United Nations International Seminar on Measurement of Disability that took place in New York in June 2001. The City Group is an informal, temporary organizational format that allows representatives from national statistical agencies to come together to address selected problems in statistical methods. It is authorized by the United Nations Statistics Division. The Budapest Initiative is the Joint Task Force on Measurement of Health Status set up in 2005 by the United Nations Economic Commission for Europe, the World Health Organization and Eurostat.

8 ICF is the World Health Organization (WHO) framework for measuring health and disability at both individual and population levels. ICF was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001 (resolution WHA 54.21) as the international standard to describe and measure health and disability.



support will be among communities. Still, methodology is relevant for communities in as much as it can factor out abuse. Abuse may be twofold: victimization of individuals who self-identify as people living with disabilities or of ethnic minority origin and the vilification or further stereotyping of groups. Against this backdrop, it would be frivolous to recommend a specific method of data collection beyond indicating a preference for the highest level of safeguards, because methodology is not the primary question. The debate within the communities focuses instead on trust vis-à-vis the agency collecting the data on the one hand and on the safeguards built in, as well as the actual sanctions imposed on those who abuse the data on the other. In conclusion, once data collection methods respect the binding core principles, they will be acceptable to minorities. Given that communities favor a consent based opt-out model, ultimately individuals would decide whether to become data subjects.

The way forward is through the active involvement of disability and ethnic minority representatives. They alone can legitimize data collection methods, categories and question sets on disability and ethnic origin which should preferably include questions on experiences of discrimination. Clearly, the involvement of representatives in later stages, such as the collection and analysis of data, would equally be beneficial.

Given the multi-level governance structures within the European Union, the process needs to start simultaneously at the European as well as the national levels. While in some instances national stakeholders regularly collaborate with their European counterparts — for example, statistical offices with Eurostat and data protection agencies with the European Data Protection Supervisor — other relevant national stakeholders may need a more formalized forum for cooperation. Thus, national equality bodies, ombudsmen's offices and indeed, disability and ethnic minorities that either lack an EU-level umbrella organization or collaborate in NGO structures only should be assisted through regular and formalized consultation processes.

The binding core principles of equality data collection must find their way into European practice through European law, because soft measures have not so far yielded tangible results on the ground. Given their binding nature, the core principles should be set out in a legal instrument taking the form of a Commission recommendation on the collection of equality data with a view to defending legal claims, assessing equality policies, and designing positive action measures under EU antidiscrimination law or specific provisions in the draft Data Protection Regulation. The material and personal scope needs to correspond to the European antidiscrimination law of which the implementation is in question. A reporting obligation should be imposed on Member States in relation to both objectives. The legal basis of such a recommendation is provided by Article 19 of the Treaty on the Functioning of the European Union (TFEU), Article 8.4 of the Data Protection Directive, the antidiscrimination directives — particularly Articles 5 and 15 of the Racial Equality Directive — and Article 31 of the CRPD. The reporting obligation may ensure that minority groups are consulted in order to identify categories and question sets and that the use of proxies and/or third-party identification is discontinued. Alternatively, practices that do not comply with the Data Protection Directive need to be challenged under that instrument. Equality data will then pave the way to equal opportunities planning and monitoring.

- There is a widely held belief that *the law* prohibits any collection of sensitive data pertaining to disability and ethnic origin.
- Equality data can be collected in compliance with the exemptions enumerated in Article 8 of Directive 95/46/EC.
- Most EU Member States refuse to collect disaggregated equality data mainly because of a narrow interpretation of national data protection laws. At the same time, they collect data that reveal disability and ethnic origin on the basis of third-party identification and proxies.
- In general, disability and ethnic minority communities are not consulted on their data needs.
- Public debate on the issue is scarce.
- EU legislation does not impose a straightforward obligation on Member States to collect equality data, the exception being disability data (Article 31 CRPD). Arguably, a data collection duty complementing mandatory positive action measures may be construed.

## 1. Introduction

Data are needed to ensure equality: to measure inequalities, to target social policies and to monitor their implementation, and to design remedies including positive action measures. This seems to be a generally accepted fact at the European level. Yet, despite the abundance of materials on this matter produced over the last ten years by European Union and Council of Europe institutions, little progress has been made on the ground. The more sensitive the protected ground of discrimination, the greater the perceived challenges and threats to equality data collection. Arguably, in the present continental European context, sensitivity may better serve the purposes of those who do not wish to collect equality data. In the majority of Member States reviewed in this report, the present data protection laws strike the right balance between individuals' right to equal treatment and their right to privacy. However, in practice, the latter right often trumps the former. Steps need to be taken to prevent "no equality data from meaning no equality."<sup>9</sup>

Legal provisions cannot forbid us from ascribing a certain disability or ethnic origin to another person on the basis of our own assumptions. Curiously, an individual's ethnic origin, religion, sexual orientation or disability as perceived by a third party may not even correspond to these personal characteristics as identified by the individual him/herself. Moreover, a person's identity in terms of these characteristics is fluid and may change over time. That, however, does not necessarily impact on how this person is perceived by others. The only grounds of discrimination for which collecting data has not been problematic are those of gender and age.<sup>10</sup>

### 1.1 Note on concepts: equality data, ethnic data, disability, race, and ethnic origin

The Racial Equality Directive<sup>11</sup> covers discrimination based on race and ethnic origin, while the Employment Equality Directive<sup>12</sup> pertains to disability among other grounds. However, European law does not define these grounds. On the other hand, international and national laws contain definitions and it is noteworthy that the Starting Line Group (SLG)'s initiative that ultimately led to the adoption of the Racial Equality Directive in 2000 – on which the Employment Equality Directive was also modeled — originally targeted race and ethnic origin as well as religion.<sup>13</sup> Discussions with stakeholders — particularly at the national level – during the drafting phase had already revealed the many taboos attached to the term race and the

9 In 2010, the Roma Initiative Office (RIO) published the report *No Data, No Progress*, demonstrating the difficulties of assessing progress made in the framework of the Decade for Roma Inclusion. The report mapped the (un)availability of data on the Roma population in 12 countries: Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Czech Republic, Hungary, Macedonia, Montenegro, Romania, Serbia, Slovakia, and Spain.

10 See, for example, the equality indicators published by Eurostat relating to (only) gender and age: [http://epp.eurostat.ec.europa.eu/portal/page/portal/employment\\_social\\_policy\\_equality/equality](http://epp.eurostat.ec.europa.eu/portal/page/portal/employment_social_policy_equality/equality).

11 Council Directive (EC) 2000/43 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin [2000] OJ L180/22 (Racial Equality Directive).

12 Council Directive (EC) 2000/78 establishing a general framework for equal treatment in employment and occupation [2000] OJ L303/16 (Employment Equality Directive).

13 The Starting Line Group was a coalition of more than 400 non-governmental actors from across the European Union, active in the field of antidiscrimination. Jan Niessen and Isabelle Chopin, "The Starting Line and the Racial Equality Directive," in *The Development of Legal Instruments to Combat Racism in a Diverse Europe*, eds. Isabelle Chopin and Jan Niessen (Leiden: Martinus Nijhoff Publishing, 2004), 95-110.

diverse definitions of ethnic origin. However, the Starting Line Group found an ally in the European Commission at the end of the drafting process: the Commission supported the use of the term “race” in the wording of obligations incumbent on the then 15 Member States. Similarly, in relation to statistical data on the protected grounds, a Commission publication used the term “equality data,” while a Council of Europe study adopted the term “ethnic data.”<sup>14</sup> The latter, as evidenced by national stakeholder meetings, is widely used today.

The dividing line between race and ethnic origin is constructed first on the basis of “recent” migrant status and then on other, apparently political considerations. Already in 2005, the then EU Monitoring Centre on Racism and Xenophobia (the predecessor of today’s FRA) underlined that “Many EU Member States have ethnic minority groups who are not migrants or descendants of recent migrant populations, but are either indigenous or have settled in the countries a long time ago. At times these groups are referred to as national minorities, at other times as autochthonous minorities, as linguistic minorities, or simply as ethnic minorities... The status of these groups varies. Some are officially recognized minority groups with special rights and privileges, some have particular language rights and others do not have special group rights at all. The same minority might officially be recognized in some countries but not in others (e.g. the Roma).”<sup>15</sup> Still, as the UN Human Rights Committee (HRC) states: “[t]he existence of an ethnic, religious or linguistic minority in a given State party does not depend upon a decision by that State party but requires to be established by objective criteria.”<sup>16</sup>

In 2007, with a view to formulating a definition of “Roma,” the European Network of Legal Experts in the non-discrimination field analyzed the definition contained in the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD), the treaty ratified by all Member States and referenced in the Preamble of the Racial Equality Directive.<sup>17</sup> Under the ICERD racial discrimination includes “any distinction, exclusion, restriction or preference based on *race, colour, descent, or national or ethnic origin* which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life” (emphasis added). The report found this significant first because the definition eclipses the distinction between discrimination based on nationality, ethnicity or race. It also noted that the definition recognizes that the categories of color and descent are not in themselves socially relevant; it is the majority perception which makes them so. Race is recognized as a category that is applied to “individuals according to their outer appearance, skin colour being an important, but *not the only* distinguishing feature.”<sup>18</sup> Thus, conceptualizing

14 Timo Makkonen, *Measuring discrimination – Data collection and EU equality law* (Thematic report of the European Network of Legal Experts in the Non-discrimination Field, Luxembourg: Office of the Official Publications of the EC, 2007); Patrick Simon, *Ethnic statistics and data protection in the Council of Europe countries* (Thematic report of the European Commission against Racism and Intolerance (ECRI), Strasbourg: Council of Europe, 2007).

15 European Monitoring Centre on Racism and Xenophobia (EUMC), *Activities of the EUMC in 2005*, (Luxembourg: Office for Official Publications of the European Communities, 2006), Part II, 57.

16 Human Rights Committee: General Comment 23, HRI/GEN/1/Rev.7 (May 12, 2004) para. 5.2. On account of an autonomous definition of the term “ethnic minorities” in the anti discrimination context, this report does not address differences between “national” and “ethnic” minorities that often cause concern in the minority rights context.

17 Lilla Farkas, *Segregation of Roma children in education: addressing structural discrimination through the Race Equality Directive* (Thematic report of the European Network of Legal Experts in the Non-discrimination Field, Luxembourg: Office of the Official Publications of the European Communities, 2007).

18 Dagmar Schiek, “A new framework on equal treatment of persons in EC law?” *ELJ* 8 (2002): 309.

the difference as ultimately perception based reveals the social attributes of the Roma as being beyond their control. In contrast to a definition which focuses on the individual's choice to belong to a national and ethnic minority, this definition encapsulates Roma language, culture, etc., as ascriptions. It has been argued that:

...[the] inextricable connection between the concept of race and structures of domination is particularly clear in the use of ethnicity as exclusively attached to minorities. The dominant group does not see itself as an ethnic group, but as the embodiment of universal values. All other groups can therefore be described as different, where different means deviant and therefore justifies inferior treatment.<sup>19</sup>

Race, (ethnic) minority status, religion, language and cultural traditions have not always been automatically distinguished, at least not outside of national political contexts. In its Advisory Opinion of July 31, 1930, concerning the Greco-Bulgarian Communities (Opinion no. 17), the Permanent Court of International Justice stated that a (minority) community is “a group of persons living in a given country or locality, having a race, religion, language and traditions of their own and united by this identity of race, religion, language and traditions in a sentiment of solidarity, with a view to preserving their traditions, maintaining their form of worship, ensuring the instruction and upbringing of their children in accordance with the spirit and traditions of their race and rendering mutual assistance to each other.”

This pragmatic view of race and ethnic origin is espoused by both the Court of Justice of the European Union (CJEU) and the European Court of Human Rights (EctHR). In *Feryn*, the CJEU skated over potential differences between the terms “Moroccans,” “immigrant,” “race”, and “ethnic origin” when establishing direct discrimination under the Racial Equality Directive.<sup>20</sup> Similarly, when discussing the material scope of the Racial Equality Directive in relation to documents on civil status issued in a particular language using a particular alphabet, it did not concern itself with the definition of ethnic origin.<sup>21</sup>

Likewise, the European Court of Human Rights in *Timishev v. Russia* and subsequent Roma-related cases held that discrimination based on ethnicity is a form of racial discrimination, which is a particularly invidious form of discrimination. In *Timishev*, it explained that “Whereas the notion of race is rooted in the idea of biological classification of human beings into subspecies according to morphological features such as skin colour and facial characteristics, ethnicity has its origin in the idea of societal groups marked by common nationality, tribal affiliation, religious faith, shared language, or cultural and traditional origins and backgrounds.”<sup>22</sup>

Discussions around disability are somewhat different and international norm setting is also more recent in this field. The preamble of the CRPD pays tribute to this fact when it states that disability is an “evolving concept.” Under Article 1, “Persons with disabilities include those who

19 Sandra Fredman, “Combating racism with human rights,” in *Discrimination and Human Rights: The Case of Racism*, in Sandra Fredman, ed., (Oxford: Oxford University Press, 2001), 11.

20 Case C-54/07, Centrum voor gelijkheid van kansen en voor racismebestrijding v. Firma Feryn NV [2008] ECR I-5187.

21 Case C-391/09, *Malgożata Runevič-Vardyn, Łukasz Paweł Wardyn v. Vilniaus miesto savivaldybės administracija and others* [2011] ECR I-03787.

22 *Timishev v. Russia* (2007) 44 EHRR 37, para. 55.

have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.” Under Article 2, discrimination based on disability includes the denial of reasonable accommodation.

In *Chacón Navas* the CJEU defined disability, for the purposes of the Employment Equality Directive, as “a limitation which results in particular from physical, mental or psychological impairments and which hinders the participation of the person concerned in professional life.”<sup>23</sup> Reportedly, four different approaches to the definition of disability exist at the national level. Many Member States, including Bulgaria and Romania, do not have a definition of disability in their nondiscrimination legislation. Others, such as Sweden, have a definition of disability specifically in the context of nondiscrimination legislation. As Lawson and Waddington note, in general “such definitions seem to be in line with the approach developed in *Chacón Navas*, and consist of three elements: (1) the requirement that an impairment exists, defined as some sort of restriction or limitation caused by a medical condition; (2) the requirement that this impairment impacts on an individual’s capacity to take part in employment, or in everyday life in general; and (3) the requirement that the impairment be permanent or have lasted, or be likely to last, for a significant period of time.”<sup>24</sup> A few national antidiscrimination laws “borrow” definitions from other legislation, often in the field of social security. “The use of such limited definitions for the purposes of non-discrimination legislation almost certainly breaches the Directive and is not in line with the Court’s ruling in *Chacón Navas*.”<sup>25</sup> Similar concerns arise in relation to Germany and France in relation to national rules defining disability for the purposes of reasonable accommodation.<sup>26</sup>

In the field of education, “special educational needs,” a term related to but not identical with disability, is used to describe learning disabilities, communication disabilities, emotional and behavioral disorders, physical disabilities, and developmental disabilities. According to UNESCO, special needs education is “Education designed to facilitate the learning of individuals who, for a wide variety of reasons, require additional support and adaptive pedagogical methods in order to participate and meet learning objectives in an educational programme. Reasons may include (but are not limited to) disadvantages in physical, behavioural, intellectual, emotional and social capacities. Educational programmes in special needs education may follow a similar curriculum as that offered in the parallel regular education system, however they take individuals’ particular needs into account by providing specific resources (e.g., specially trained personnel, equipment, or space) and, if appropriate, modified educational content or learning objectives. These programmes can be offered for individual learners within already existing educational programmes, or be offered as a separate class in the same or separate educational institutions.”<sup>27</sup>

23 Case C-13/05, *Sonia Chacón Navas v. Eurest Colectividades SA* [2006] ECR I-6467.

24 Anna Lawson and Lisa Waddington, *Disability and non-discrimination law in the European Union, An analysis of disability discrimination law within and beyond the employment field* (Thematic report of the European Network of Legal Experts in the Non-discrimination Field, Luxembourg: Office of the Official Publications of the EC, 2009), 7-8.

25 Ibid.

26 Ibid.

27 UNESCO, “Revision of the International Standard Classification of Education (ISCED)” (resolution 36C/19, 2011), 83.

The outstanding issues on disability data are the further demedicalization of the question sets developed by the Washington Group and the Budapest Initiative<sup>28</sup> in the aftermath of the adoption of the CRPD on the one hand, and the defining of the data sets that should be collected in order to measure differences in achievement based on disability and identify avenues for further policy initiatives on the other.

Based on the foregoing, this report pursues a pragmatic approach while relying on the rich texture of recent academic debate on race — particularly its interconnection with ethnic origin and religion.<sup>29</sup> It does not, however, aspire to further theorize on these concepts. Rather, it weaves into the debate views from the communities targeted by equality data collection or suffering from its lack. Finally, it does not seek to resolve the outstanding issues of apparently arbitrary national definitions of disability on the one hand and ethnic origin on the other, nor the similarities and differences between race and ethnic origin and the linkages between race and migration status. The latter was not a central element of discussions at the national stakeholder meetings. Moreover, differences between race and ethnic origin that would be relevant to the present ethnic data agenda were not identified.

Two important issues were, however, discussed during the national stakeholder meetings: the categorization of and questions relating to experiences of discrimination among racial and ethnic minorities. We understand that the geographical origin of certain groups and the everyday experience of discrimination — whether based on a person’s origins outside of the old continent or religions other than Christian — are common threads that racial and ethnic minorities across the seven countries seek to weave into the debate on equality data collection. While national stakeholders seemed familiar with the term “ethnic data,” community representatives did not voice demands for other terms to be used. Bearing in mind the instructive insight provided by the UN Human Rights Committee on the constitution of ethnic minorities quoted above,<sup>30</sup> our conviction is that considerations of race as well as ethnic origin can be captured by the term “ethnic data” and we shall therefore use this term interchangeably with “data based on ethnic origin” throughout the report, unless the exploration of nuances otherwise requires.

## 1.2 Purpose of the research

In recent years, various stakeholders have been faced with a scarcity of equality data in the European Union. International treaty monitoring bodies have called for the collection of equality data to assess the impact of state policies. Official ethnic data show discrepancies with unofficial ethnic data, while the categories used to collect disability data — especially data on milder forms of disability — vary greatly across the Member States. This report employs the term “equality data” to denote all types of disaggregated data used to assess the

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28 Washington Group on Disability Statistics, Budapest Initiative, and United Nations Economic and Social Commission for Asia and the Pacific, “Development of disability measures for surveys: the Extended Set of Functioning”, 2011, [http://www.cdc.gov/nchs/data/washington\\_group/Development\\_of\\_Disability\\_Measures\\_for\\_Surveys\\_The\\_Extended\\_Set\\_on\\_Functioning.pdf](http://www.cdc.gov/nchs/data/washington_group/Development_of_Disability_Measures_for_Surveys_The_Extended_Set_on_Functioning.pdf).

29 A summary of which is given in Michele Grigolo, Costanza Hermanin, and Mathias Möschel, “How does race count in fighting discrimination in Europe?” *Ethnic and Racial Studies*, 34:10 (2011): 1751-1769.

30 Human Rights Committee, (see footnote 16 above).

comparative situation of a specific group at risk of discrimination. This implies that such data can be collected using different techniques, i.e., in the framework of public statistics (censuses, administrative files), ad hoc surveys, internal monitoring by enterprises or public administrations, judicial system data, and data on complaints received by equality bodies. This report maps the state of the art regarding collection of equality data on ethnic origin and disability in Europe, including major developments at the EU level and in seven Member States. The seven countries were selected using the following criteria:

- they were potential providers of best practices for legislation on and practices of data collection in Europe (Ireland, Sweden);<sup>31</sup>
- they had a restrictive approach to or legislation on the collection of equality data (France, Hungary);
- they were countries where there is little debate on the issue, but where the lack of data directly affects the implementation of antidiscrimination legislation (Bulgaria, Germany, and Romania).

The research, however, casts doubt on this classification of the seven countries, as is evidenced by the findings detailed below.

The report focuses on public education – except for in France where, in the light of our preliminary assessment of the national context, it covers public employment.<sup>32</sup> Public education is a field covered by the EU Racial Equality Directive, the relevant UN Conventions<sup>33</sup> and the European Convention on Human Rights (ECHR).<sup>34</sup> Although the scope of the Employment Equality Directive does not extend protection against discrimination on the ground of disability to the field of education, it certainly covers this ground in vocational training, retraining and university education. Moreover, public education is a public service which is funded by the State and is available to all children within the European Union. In addition, education is compulsory for all and it is the only service in which every child residing in the European Union must participate. Education is an empowerment right, a precondition to entering the employment market and exercising other rights. Thus, the lack of equality data in this field is of paramount importance. Similarly, public employment is covered by the legal instruments cited above, except for the ECHR – although Protocol 12 to the Convention covers this field as well.<sup>35</sup> In France, public employment represents roughly 20 percent of the total employment and thus equality data collection in this field is of significance.

31 Please note that although these countries were thought to be potential providers of best practice, neither of them proved to be in any way exemplary with regard to their legislation, policy and practices related to the collection of ethnic and/or disability data in the field of public education.

32 Experts advising the Open Society Foundations and the Migration Policy Group during the initial stage of this project feared that work on public education in France would have a disproportionately negative impact on support for an equality data campaign as the educational system is generally believed not to engender discrimination, unlike other contexts such as recruitment for employment.

33 In particular, the UN Convention on the Elimination of all Forms of Racial Discrimination (CERD), adopted on December 21, 1965 and the UN Convention on the Rights of Persons with Disabilities (CRPD), adopted on December 13, 2006.

34 Convention for the Protection of Human Rights and Fundamental Freedoms adopted on November 4, 1950.

35 Protocol no. 12 to the Convention for the Protection of Human Rights and Fundamental Freedoms, adopted on November 4, 2000.



Following a desk review of previous research, policy and academic studies, this synthesis report provides a summary of seven national reports drafted using a questionnaire developed by MPG and deliberations from the stakeholder meetings held in the seven countries.<sup>36</sup> The synthesis overviews the main legal and policy provisions in the seven Member States selected, presenting the findings from these countries highlighting as far as possible differences and commonalities as well as best and worst practices. It seeks to indicate viable methodological options for equality data collection with the aim of monitoring equality in the field of public education. The report summarizes the views of both national experts and relevant stakeholders on strategies to advocate or litigate for more equality data at the national and European level.

The seven national reports describe (a) antidiscrimination law and equality duties with respect to race, ethnic origin and disability; (b) provisions regulating access to information rights; (c) transparency requirements in the public and private sectors in relation to information on students' — in France employees' — profiles; and d) domestic data protection provisions regulating collection and processing of sensitive data (with a special focus on race, ethnic origin, and disability). The report also reviews the most recent publications, surveys, and debates on equality data collection at the EU and national level. Academic publications, NGO reports, reports by international monitoring bodies, newspaper and magazine articles, opinion polls, and publications by political parties, government agencies, and statistical offices are included in the review.

### 1.3 Statement of the issue

Data on one's ethnic origin and health status — including disability — is classified as sensitive. Therefore, European law dictates that data on these characteristics must be collected on the basis of informed consent, and possibly as a result of self-identification, if such data collection is to comply with legal and ethical standards. However, it is widely held that in public education/employment ethnic data are not collected, whereas disability data are often collected on the basis of third-party identification and medical assessment.

As demonstrated below,<sup>37</sup> the European Union and the Council of Europe have laid the groundwork for Member States that wish to collect equality data. However, changes are not visible. More precisely, guidance, standards, data collection forms, handbooks and other practical materials implementing the national laws that govern the collection of equality data are slow in coming.

Paradoxically, the very *sensitive* nature of the protected grounds is invoked as the single most important factor preventing legislation on equality data collection. As borne out in *Galina Meister*, this sensitivity has propelled even the Court of Justice of the European Union (CJEU)

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36 National stakeholder meetings were held as follows: Bulgaria: August 27-29, 2014; Germany: March 10-12, 2014; Hungary: March 24-26, 2014; Ireland: July 21-23, 2014; Romania: August 25-27, 2014; Sweden: April 28-30, 2014; France: May 26-28, 2014. MPG is grateful to Claire Fernandez, policy officer of the European Network Against Racism, for her invaluable help in recording proceedings and recommendations arising from stakeholder consultations.

37 See "Antecedents," section 2 of this report.

to sidestep the issue of processing ethnic data — even if that would appear indispensable in order to accord effective judicial remedy against discrimination.<sup>38</sup>

At the practical level, an *equality data paralysis* seems to hold most of Europe hostage. However, it does not extend to all the grounds protected at the EU level. It does not seem to hinder equality data collection on age and gender that are viewed as “objective” characteristics. In fact, data on these grounds are readily available. Ethnic data collection is the most contentious. Curiously, the sensitive nature of one’s health status does not prevent disability data from being collected in public education on the basis of third-party identification. The concern in this respect is indeed the lack of self-identification based data in public education/employment, the incompatibility of identification questions with the concept of disability enshrined in the UN Convention on the Rights of Persons with Disabilities (CRPD) and CJEU case law,<sup>39</sup> as well as the difficulty of linking data pools at the national levels as a result of the failure to standardize disability question sets.

What is the difference between the grounds of discrimination protected by EU law with regard to the collection of equality data? While some data categories might possibly be more “objective” than others, historically more contentious data on ethnic origin and disability too can be and are collected under certain conditions. This report therefore seeks to assess how equality data are collected in a sample of Member States regarding the grounds of ethnic origin and disability in the field of public education or public employment.<sup>40</sup> It examines how societal attitudes have shifted,<sup>41</sup> the state of affairs regarding the relevant legislation, what arguments have been utilized in overcoming moral, political, and legal obstacles, and what further advocacy and legal action needs to be taken to ensure equality data collection based on ethnic origin and disability.

Finding ways to collect equality data on the grounds of ethnic origin and disability is a timely initiative, notably because — as many argue — such data collection is necessary for the proper transposition and implementation of the 2000 antidiscrimination directives, although the directives per se do not require it. Moreover, the implementation of the directives has implications on the implementation of UN Conventions — such as the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) and the CRPD. While the directives, on the one hand, permit positive action on a wide scale for ethnic origin and in the field of employment for people with disabilities,<sup>42</sup> they also impose an obligation on Member

38 Case C-415/10, *Meister v. Speech Design Carrier Systems* [2012] OJ C 165/4. The Court found that EU law does not entitle “a worker who claims plausibly that he meets the requirements listed in a job advertisement and whose application was rejected to have information indicating whether the employer engaged another applicant at the end of the recruitment process”, basing this finding in part on legislation protecting the data of the other (potentially successful) candidate(s). For further details, see: Lilla Farkas, “Getting it right the wrong way? The consequences of a summary judgment: the *Meister* case,” *European Anti-Discrimination Law Review* 15 (2012), 23-33.

39 Cases C-13/05, *Chacón Navas*, and C-303/06 S. *Coleman v. Attridge Law and Steve Law* [2008] ECR I-05603.

40 France (in the field of public employment), Bulgaria, Germany, Hungary, Ireland, Romania, and Sweden (in the field of public education).

41 See Eurobarometer, *Special Eurobarometer 263, Discrimination in the European Union* (Brussels: European Commission, 2006).

42 Compare the material scopes of Directives 2000/43/EC and 2000/78/EC.

States to ensure that effective, proportionate, and dissuasive remedies<sup>43</sup> against discrimination exist at the national level. Arguably, in certain instances only positive action qualifies as such a remedy, but in order to instate positive measures, Member States must have data on the communities targeted. The UN Conventions, on the other hand, impose obligations on states parties to introduce mandatory positive action measures if and when necessary. There is also case law emerging from the European Court of Human Rights — most prominently in relation to the Roma in the fields of education and housing — that supports mandatory positive action.<sup>44</sup>

The equality bodies designated under the Racial Equality Directive as the specialized bodies responsible for assisting victims of discrimination and providing independent reports and recommendations on issues of discrimination undeniably have a role to play in this field. The practice of data collection on complaints received by the equality bodies varies considerably between the Member States. Equality bodies were established in compliance with the EU antidiscrimination directives, and although many keep records of the number of complaints they receive, this is only seldom disaggregated according to the grounds of discrimination. The data available is collected by Equinet (the Brussels-based umbrella organization bringing together Member States' equality bodies), as well as the European Union Agency for Fundamental Rights (the Fundamental Rights Agency, FRA).

The national experts authoring the country reports maintain that disability data in public education/employment are collected in an ad hoc manner, which may not facilitate the fight against discrimination as envisaged by the antidiscrimination directives and/or allow for an assessment of the existence of discrimination. Efforts to harmonize definitions and data collection practices, however, are mainly being carried out at the level of the CRPD and, to a lesser extent, at the level of the European Union. In Brussels, negotiations on the “Horizontal Directive”<sup>45</sup> that would extend protection from discrimination on the ground of disability (as well as religion and belief, age, and sexual orientation) beyond the field of employment are not progressing, and the focus of institutions seems to have shifted from extending antidiscrimination provisions to providing more accessibility to persons with disabilities in the internal market. However, protection against discrimination on grounds of disability has been indirectly extended beyond the field of employment through the ratification by the European Union of the CRPD.

While the EU can measure the progress made by the transposition of the antidiscrimination directives, it appears next to impossible to systematically measure the impact of EU funded projects on racial and ethnic minorities or people with disabilities.<sup>46</sup> Clearly, the lack of handbooks, guidelines, and standards pertaining to equality data collection renders such

43 Article 17 of Directive 2000/78/EC and Article 15 of Directive 2000/43/EC.

44 See in particular *Horváth and Kiss v. Hungary* (2013) 57 EHRR 31.

45 European Commission Proposal for a Council Directive implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation, COM (2008) 426.

46 The Commission published its latest report on the implementation of both 2000 antidiscrimination directives in January 2014: “Joint Report on the application of Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin (‘Racial Equality Directive’) and of Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation (‘Employment Equality Directive’)” COM (2014) 2.

systematic overview impossible. Indeed, the impact of social policy related funding is measured in an ad hoc manner whose compatibility with national legislation and/or EU and international law is not controlled.

Member States do not appear ready to address the equality data paralysis even at the political level, although societal attitudes in some countries are shifting towards the permissibility of equality data collection, and target groups in some countries are eagerly awaiting real change on the ground. Bearing in mind the on-going efforts within both the Council of Europe and the European Union — most recently before the European Parliament where the “Data Protection Package”<sup>47</sup> was adopted at first reading on March 12, 2014 — this report seeks to provide further impetus to a practical resolution of the issue.

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<sup>47</sup> European Commission Proposal for a regulation of the European Parliament and of the Council on the protection of individuals with regard to the processing of personal data and on the free movement of such data (General data protection regulation), COM (2012) 11 final.

## 2. Antecedents: European-level research and legal framework

### 2.1 Legal and policy frameworks for equality data collection in Europe

Council of Europe Convention no. 108,<sup>48</sup> concluded under the auspices of the Council of Europe, and EU Directive 95/46/EC<sup>49</sup> form the basis for national legislation governing equality data collection in the countries under review. Data protection law is widely perceived as prohibiting equality data collection altogether, although it in fact permits such activities if they remain within the exception clauses. While the Council of Europe focuses on ethnic data, the EU has also paid attention to other grounds, including disability. The EU antidiscrimination directives take note of the importance of statistical data in legal proceedings, in particular to establish indirect discrimination. European law does not impose an obligation on Member States to collect equality data — especially not in the policy field. The adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2006 gave impetus to work on disability data collection.

Seemingly oblivious to the debates at the state level, statisticians have been collecting data on ethnic origin and disability-based discrimination. The Fundamental Rights Agency (FRA) regularly surveys perceptions of discrimination on all the grounds covered by European law, Eurostat collects data through the European Social Survey (ESS), while the Organisation for Economic Co-operation and Development looks at discriminatory trends in education in its Programme for International Student Assessment (PISA).

#### Council of Europe: Focus on race and ethnic origin

The European Commission against Racism and Intolerance (ECRI) has been advocating the collection of ethnic data since the 1990s.<sup>50</sup> ECRI calls on governments to collect equality data understood as “statistics broken down by citizenship, national/ethnic origin, language and religion” in order to assess the effectiveness of policies targeting ethnic minority groups.

In 2006, ECRI held consultations with NGOs and commissioned a report that laid the groundwork for ethnic data collection through national censuses.<sup>51</sup> The report collected the opinions of NGOs, national statistical offices, data protection authorities — and equality bodies on whether ethnic data should be collected, and if so, under what safeguards and for what purposes. It concluded that out of the 42 Council of Europe countries covered by the study,

48 Council of Europe Convention for the protection of individuals with regard to automatic processing of personal data, adopted in Strasbourg on January 28, 1981. The Council of Europe’s Convention no. 108 requires that appropriate safeguards are in place to render the processing of sensitive data legitimate. The permissibility of processing depends on the quality (“appropriateness”) of the national safeguards provided by the country in question.

49 Directive (EC) 95/46 of the European Parliament and of the Council on the protection of individuals with regard to the processing of personal data and on the free movement of such data [1995] OJ L 281/31 (Data Protection Directive). The Data Protection Directive contains a prima facie prohibition on processing of sensitive data (Article 8.1), but it also provides for significant and wide exceptions to this main rule (Article 8.2).

50 See, e.g., ECRI General Policy Recommendation no. 4 on national surveys on the experience and perception of discrimination and racism from the point of view of potential victims, adopted on March 6, 1998.

51 Patrick Simon, *Ethnic statistics and data protection in the Council of Europe countries* (Thematic report of the European Commission against Racism and Intolerance (ECRI), Strasbourg: Council of Europe, 2007).

22 collect data on ethnicity (usually termed “nationality”), 24 on religion and 26 on language (most commonly mother tongue). Notably, however, in the old EU Member States only two countries collect ethnic data, while three collect data on language and six on religion.<sup>52</sup> The report notes that racial or ethnic origin is not defined in law, which renders data collection cumbersome and dependent on the use of proxies such as nationality, country of birth, name and language. Twenty-three characteristics are used across the Council of Europe to denote ethnic origin. Consent – informed, voluntary and possibly in writing — is the key condition governing ethnic data collection across the Council of Europe. The report concludes that data collection schemes observed in the Belgium, Netherlands, and the United Kingdom could be replicated elsewhere without major policy changes.

### European Commission: Mapping data categories and methodologies

The European Commission has focused on the need for equality data since 2000, but the bulk of the studies discussed below were concluded before the accession of the new Member States. The Commission has been vocal about the need to collect more equality data. In a green paper published in 2004 it identified the lack of statistical information — in most EU Member States — on the groups protected by the antidiscrimination directives as a serious obstacle to policy implementation and analysis in the field of antidiscrimination.<sup>53</sup> The same year, it published the *Comparative study on the collection of data to measure the extent and impact of discrimination within the United States, Canada, Australia, the United Kingdom and the Netherlands*.<sup>54</sup> The study sought to develop and disseminate “methodologies and indicators to assess the effectiveness of antidiscrimination policy and practice.”<sup>55</sup> It underlined that “[various data collection] logics are combined and sometimes conflict with each other.”<sup>56</sup> While policies favor self-reporting with multiple choices because they “seek to match statistical categories” with the groups targeted by policy schemes, the principle behind statistical/scientific templates, as well as administrative and legal registers, is to have well defined and exclusive (i.e., “objectivistic”) categories for the sake of comparison and analysis.<sup>57</sup> Comparisons between national categories used both for ethnic origin and for disability show that “categories are contingent on national history,” but also reflect the level of trust in ethnic minorities and persons living with disabilities in self-identifying “correctly.” The difference between the categorization used in the 2001 UK census and in the practice of the Dutch statistical agency aptly demonstrates the two extremes of approaches to categorization. In the United Kingdom, the census categories are *openly ethno-racial*, with the main categories of “White,” “Mixed,” “Asian or Asian British,” “Black or Black British,” and “Chinese or other ethnic group” broken down into further subcategories with the option for respondents to freely state any subcategory not specifically listed. In contrast, in the Netherlands the classification standard is based on the concept of “generation” — an allegedly

52 The old Member States where ethnic data is collected are Ireland and the United Kingdom. For the complete list of types of data collected in the Council of Europe Member States as recorded by Simon, please see Appendix IV of Simon, *Ethnic Statistics and Data Protection*, 113-117.

53 European Commission Green Paper on Equality and non-discrimination in an enlarged European Union, COM(2004) 379 final [not published in the Official Journal], 22.

54 European Commission, *Comparative study on the collection of data to measure the extent and impact of discrimination within the United States, Canada, Australia, the United Kingdom and the Netherlands*, (Luxembourg: Office of Official Publications of the EC, 2004).

55 Ibid., 5.

56 Ibid., 52.

57 Ibid.

“objective” concept that denotes a person’s foreign background. Certain regions of the world are categorized as “Western” because of the relatively high social and economic position of persons originating from that region in Dutch society. The study notes the blending of race, ethnic origin, and religion in certain cases, but rather summarily argues that this phenomenon is transitional.

The study warns that “challenges facing the collection of statistics concerning ethnic and racial origin are even more acute in the case of disability.”<sup>58</sup> The definition of disability may pose challenges, and then technical difficulties may arise in collecting data depending on the definition of the category. Moreover, the concept of reasonable accommodation that is the main antidiscrimination scheme adopted at the EU level for persons with disabilities requires statistical tools that are distinct from more classic methodologies that monitor developments. The final recommendations include the following: (i) to advocate for a mandatory monitoring system involving penalties; and (ii) to provide guidelines for data collection and standards for categorization. The study recalls that the process of redefining categories must involve civil society organizations.

The European Commission published the *Study on data collection to measure the extent and impact of discrimination in Europe*<sup>59</sup> aiming to extensively map the existing mechanisms and entities involved in data collection on discrimination. It formulated a wide range of recommendations targeting all stakeholders, from national to EU level, from the police through equality bodies to national statistical offices. Ninety-three percent of the respondents said that data collection on discrimination improves the situation of a group.<sup>60</sup>

The study was followed by a handbook on equality data,<sup>61</sup> published in 2007, which provides guidance on why and what kind of equality data to collect, and shows how that data can be gathered. The handbook includes recommendations to decision-makers, civil servants, members of equality groups, equality bodies, and NGOs, as well as statisticians, researchers, and employers. Particularly relevant for the purposes of the present report is chapter 3.4 on administrative registers. As the handbook notes, typical administrative registers include education and employment registers that contain information on e.g., school attendance, educational attainment, labor market participation and income. While these records are often decentralized, they can usually be accessed by national statistical agencies. The handbook identifies the major limitation of administrative registers as the fact that they are purpose bound and therefore may not contain the information necessary to identify individuals who belong to an ethnic minority or live with disabilities. Given that disability data are usually contained in registers dealing with social services or benefits, they are likely to deal only with the more severe forms of disability. The handbook recommends that: (i) a survey be conducted of what information is collected by means of population censuses, administrative registers,

58 Ibid., 67.

59 Niklas Reuter, Timo Makkonen, Olli Oosi, *Study on data collection to measure the extent and impact of discrimination in Europe* (Luxembourg: Office of Official Publications of the EC, 2004).

60 Ibid., pp 168-170.

61 Timo Makkonen, *European handbook on equality data: Why and how to build to a national knowledge base on equality and discrimination on the grounds of racial and ethnic origin, religion and belief, disability, age and sexual orientation* (Luxembourg: Office of Official Publications of the EC, 2007).

and surveys; and (ii) investigations take place as to whether the ethnic and disability categories (variables or proxy indicators) surveyed through these mechanisms could be expanded so as to cover ethnic origin and disability. The handbook cites as a commendable example of good practice the “Towards common measures for discrimination” project whose purpose was to develop methodological models for the investigation of ethnic discrimination using data obtained by linking several administrative registers together. The project focused on the Czech Republic, Denmark, the Netherlands, Norway, and Portugal.<sup>62</sup>

In 2011, the Commission’s EU Framework for National Roma Integration Strategies up to 2020 added another item to the list of publications calling for more equality data.<sup>63</sup> While the impetus provided by this document is limited to the policy field, a clear legal obligation is taking shape in relation to disability data collection at both Member State and EU levels. The EU has ratified the CRPD, whose Article 31 entitled “Statistics and data collection” recognizes State Parties’ obligations to collect reliable and comparable data to facilitate the formulation and implementation of national policies and programs that promote the rights of persons with disabilities and give effect to the CRPD.

In a communication adopted in 2008, the Commission stated that it was “exploring the possibilities of: (i) collecting statistics regularly on the scale and impact of discrimination in conjunction with the Member States’ statistical authorities under the Community Statistical Programme, in particular on grounds of racial and ethnic origin, religion/belief, and sexual orientation, where there is still a lack of information; and (ii) setting up an EU-survey module on discrimination.”<sup>64</sup> Finally, in January 2014, the Commission adopted its second implementation report on the Racial and Employment Equality Directives, raising the “lack of equality data” as one of the main current challenges to the implementation and application of the Directives.<sup>65</sup>

### Eurobarometer: Mapping the support for equality data collection

In 2006, the Special Eurobarometer 263 on discrimination in the European Union was conducted. It found that within the general population, “on average, there is a *broad degree of willingness* among the European public to provide personal information as part of a census on an anonymous basis to combat discrimination, and *relatively little resistance*” (emphasis added).<sup>66</sup> Across the EU, a majority of respondents were in favor of providing personal information as part of a census to help combat discrimination: 75 percent as regards data in

62 Eero Olli and Birgitte Kafod Olsen, *Towards Common Measures for Discrimination II - Recommendations for Improving Measurement of Discrimination* (Oslo: The Equality and Antidiscrimination Ombud & The Danish Institute for Human Rights, 2006).

63 European Commission, “Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions: EU Framework for National Roma Integration Strategies up to 2020” COM (2011) 173 final.

64 European Commission, “Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions: Non-discrimination and equal opportunities: A renewed commitment” COM(2008) 420, 8.

65 European Commission, “Joint Report on the application of Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin (‘Racial Equality Directive’) and of Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation (‘Employment Equality Directive’)” COM (2014) 2., 5-6.

66 Eurobarometer, “Special Eurobarometer 263, Discrimination in the European Union” (Brussels: European Commission, 2006), 28.



relation to ethnic origin and 71 percent in relation to health status. Nineteen percent would be opposed to data collection on ethnic origin and 25 percent regarding health status, while the proportion of those who did not know was 6 percent and 5 percent respectively. There were negligible differences between old and new EU Member States when it came to supporting equality data collection, and sociodemographic analyses indicate that people's willingness to provide information depends on their age and education: willingness declines with age and increases with the age when they leave education.<sup>67</sup> The country-specific data provided in the annex to the Special Eurobarometer with regard to the countries selected for this research show the following:

#### Support in general population for equality data collection in census on an anonymous basis

	Totally + somewhat in favor – ethnic origin (%)	Totally + somewhat in favor – health status (%)
<b>Bulgaria</b>	63 + 22 = 85	62 + 22 = 84
<b>France</b>	45 + 34 = 79	40 + 33 = 73
<b>Germany</b>	44 + 27 = 71	38 + 26 = 64
<b>Hungary</b>	28 + 36 = 64	27 + 37 = 64
<b>Ireland</b>	36 + 33 = 69	35 + 31 = 66
<b>Romania</b>	54 + 19 = 73	54 + 20 = 74
<b>Sweden</b>	67 + 16 = 83	63 + 15 = 78

The country-specific data throw into question the political discourse that portrays equality data collection as a social taboo. Curiously, ethnic data collection has higher support in societies under review than disability data collection. Notably, however, the attitudes of the general public on equality data collection have not been canvassed since 2006.

Five Eurobarometer surveys contain some form of disability identification questions, especially focusing on discrimination. One focuses specifically on disability and includes discrimination questions (Eurobarometer 54.2, 2001, “Attitudes of Europeans to Disability”), and four are on discrimination generally while including questions concerning disability.<sup>68</sup>

The latest, Special Eurobarometer 393, was published in November 2012.<sup>69</sup> It found that the three most widely perceived grounds of discrimination are ethnic origin (56 percent), disability (46 percent) and sexual orientation (46 percent).<sup>70</sup> Overall, 16 percent of EU citizens reported having suffered discrimination, but only 4 percent considered themselves as belonging to an ethnic minority group and 3 percent as belonging to the disability community.<sup>71</sup>

67 Ibid., 29.

68 Eurobarometer, Eurobarometer 57.0 of 2002, 65.4 of 2006, Flash Eurobarometer 232 of 2008 and 69.1 of 2008 on “Discrimination in the European Union” (Brussels: European Commission).

69 Eurobarometer, “Special Eurobarometer 393 Discrimination in the EU in 2012” (Brussels: European Commission, 2012).

70 Ibid., 7.

71 Ibid., 14.

## 2.2 Research identifying a need for reliable and adequate equality data

In 2001, the European context was mapped and dangerous practices — such as ethnic profiling — were flagged up in a book entitled *Ethnic Monitoring and Data Protection: The European Context*.<sup>72</sup> In 2007 a report entitled *Measuring Discrimination — Data Collection and EU Equality Law* was published.<sup>73</sup> In this report, Makkonen listed in detail the definitions, classifications, and categories to be used and methods of identification that may be employed when mapping ethnicity.

In 2008, the FRA developed a survey covering 23,500 persons with migrant or minority backgrounds across the European Union to measure the degree of discrimination (the EU-MIDIS survey).<sup>74</sup> This survey included a question on willingness to provide information on one's ethnic origin as part of an anonymous census if this could help to combat discrimination. Although the results varied greatly between different groups, in most countries a majority of respondents were willing to provide such information.<sup>75</sup> In 2012, in collaboration with the UNDP, the FRA surveyed Roma respondents in 11 Member States.<sup>76</sup> In its report on the implementation of the Racial Equality Directive published in January 2012, the FRA underlined the need to collect ethnic data.<sup>77</sup> In a recent opinion on the new draft Data Protection Regulation, the FRA encouraged the EU institutions to clarify the standards for collecting sensitive data and to provide EU Member States with the appropriate tools, by making explicit in the new Regulation that sensitive data may be collected for the purpose of combating discrimination based on the grounds listed in Article 21 of the European Union Charter of Fundamental Rights.<sup>78</sup> In March 2013, the FRA reported that it had met with European stakeholders and civil society organizations to map existing initiatives and challenges in collecting disaggregated ethnic data in order to move towards systematic equality data collection in Europe.<sup>79</sup> The FRA has also produced comparative research on persons with mental health problems<sup>80</sup> and collected national definitions of disability.

72 Andrea Krizsán, ed, (Budapest: Central European University Press, 2001).

73 Makkonen, *Measuring discrimination*.

74 European Union Agency for Fundamental Rights, *European Union Minorities and Discrimination Survey, Main Results Report* (Vienna, European Union Agency for Fundamental Rights, 2009)  
[http://fra.europa.eu/sites/default/files/fra\\_uploads/663-FRA-2011\\_EU\\_MIDIS\\_EN.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/663-FRA-2011_EU_MIDIS_EN.pdf).

75 European Union Agency for Fundamental Rights, *European Union Minorities and Discrimination Survey, Main Results Report*, 85, 137, 158, 179, 200 and 223. The survey canvassed opinions from major ethnic minority groups present across the EU. While on average the ex-Yugoslav, the Russian and the Eastern European immigrant population seemed to be most willing to provide data on their ethnic origin in the census for the purposes of fighting discrimination, willingness among the Turkish and North African communities also ranked high, with Somalis and the Roma ranking lower. However, even the majority of the Roma would be willing to provide ethnic data.

76 European Union Agency for Fundamental Rights and the United Nations Development Programme, *The Situation of Roma in 11 EU Member States* (Luxembourg: Publications Office of the European Union, 2012)  
[http://fra.europa.eu/fraWebsite/attachments/FRA-2012-Roma-at-a-glance\\_EN.pdf](http://fra.europa.eu/fraWebsite/attachments/FRA-2012-Roma-at-a-glance_EN.pdf).

77 European Union Agency for Fundamental Rights, *The Racial Equality Directive: application and challenges* (Luxembourg: Publications Office of the European Union: 2012), 13,  
[http://fra.europa.eu/fraWebsite/attachments/FRA-RED-synthesis-report\\_EN.pdf](http://fra.europa.eu/fraWebsite/attachments/FRA-RED-synthesis-report_EN.pdf).

78 European Union Agency for Fundamental Rights, “Opinion of the European Union Agency for Fundamental Rights on the proposed data protection reform package” (Vienna: European Union Agency for Fundamental Rights, 2012),  
<http://fra.europa.eu/sites/default/files/fra-opinion-data-protection-oct-2012.pdf>, para. 31 *et seq*.

79 “Meeting to discuss how to improve equality data collection,” European Union Fundamental Rights Agency,  
<http://fra.europa.eu/en/event/2013/meeting-discuss-how-improve-equality-data-collection>.

80 *The legal protection of persons with mental health problems under non-discrimination law* (report of the European Union Agency for Fundamental Rights, Luxembourg: Publications Office of the European Union: 2011)  
<http://fra.europa.eu/en/publication/2011/legal-protection-persons-mental-health-problems-under-non-discrimination-law>.

Finally, with a view to promoting the implementation of the CRPD, self-identification based disability identification questions (short and long sets of questions compatible with the International Classification of Functioning, Disability and Health (ICF)) have been prepared by the Budapest Initiative in cooperation with the Washington Group for Disability Statistics.<sup>81</sup> No similar project has been reported in relation to ethnic origin.

### Academic publications

Recent academic publications<sup>82</sup> stress that a clear need for equality data is generated by the adoption of the antidiscrimination directives. As the discourse moves from standard setting to practical implementation, data collection is viewed as central to developments. There is agreement that the collection of ethnic data is not prohibited by either regional, European or national laws, but the right to privacy defines the contours of safeguards applicable to the collection of sensitive data. The focus is on race and ethnicity and their interlinkages with immigration. While the common law countries' legal tradition is familiar with naming races and using racial categorization, the construction of ethnic categories presents new challenges in the continental European context. Choices between proposed and existing categories, criteria, variables, and identification questions must be made if ethnic statistics are to be collected. These choices, however, depend on the given state's attitude to its ethnic minorities and its perception of itself as a multifaceted, multicultural society.<sup>83</sup>

### The views of statisticians

The UN's Principles and Recommendations for Population and Housing Censuses stresses that "the subjective nature of the term" requires that "information on ethnicity be acquired through self-declaration of a respondent and also that respondents have the option of indicating multiple ethnic affiliations."<sup>84</sup> Beyond the informed consent requirement, statisticians also stress the following: (i) affiliation with ethnic groups is distinct from language and/or religion; (ii) affiliation with an ethnic group should not be confused with citizenship: it is better to use "ethnicity" and avoid "nationality"; (iii) free self-declarations / open questions should be used; (iv) respondents should be able to indicate more than one ethnic affiliation; (v) "none" or "not declared" should be allowed; (vi) instructions should be provided on determining the ethnicity of children of mixed couples; (vii) the basic criteria and classification procedures should be documented; and (viii) classification depends on national concepts — there are no international recommendations. In order to overcome challenges statisticians recommend consultation, publicity and information campaigns, data protection and disclosure control, testing questions carefully, using well-trained enumerators, dissemination and communication of the statistics, and adherence to the fundamental principles of official statistics.

81 The short and extended sets of identification questions are available at: [http://www.cdc.gov/nchs/washington\\_group/wg\\_documents.htm](http://www.cdc.gov/nchs/washington_group/wg_documents.htm)

82 M. Möschel, C. Hermanin and M. Grigolo, *Fighting Discrimination in Europe: The Case for a Race-Conscious Approach* (London, New York: Routledge, 2012); O. De Schutter and J. Ringelheim, *Ethnic Monitoring: The Processing of Racial and Ethnic Data in Anti-Discrimination Policies: Reconciling the Promotion of Equality with Privacy Rights* (Brussels: Bruylant, 2010); Makkonen, *Measuring Discrimination*; Makkonen, *European Handbook on Equality Data*.

83 Angeline Escafre-Dublet and Patrick Simon, "Ethnic Statistics in Europe: The Paradox of Colour-blindness" in *European Multiculturalism: Cultural, Religious and Ethnic Challenges*, Anna Triandafyllidou, Tariq Modood and Nasar Meer, eds, (Edinburgh: Edinburgh University Press 2012).

84 Department of Economic and Social Affairs Statistics Division, *Principles and recommendations for population and housing censuses, Revision 2, Draft* (New York: United Nations 2006), para. 2.143.

In 2012, Eurobarometer 393 asked questions about ethnic and disability minority status, geographical origin, parents' geographical origin — and in relation to disability, about a chronic physical or mental health problem. The European Social Survey (ESS) asks about the respondent's citizenship, country of birth, the language(s) spoken most often at home, membership of an ethnic minority in the surveying country, and finally the country of birth of the person's mother and father. The ESS does not measure residential status and length of residence.

Statisticians seem to be in favor of a model that uses question cards and combines ethnic origin as well as links to a particular geographic area — bearing in mind that the latter can capture immigration background.<sup>85</sup> Political ties to geographic areas may receive more emphasis in other proposals.<sup>86</sup>

In a recent project Anthony Heath and his colleagues adapted the Australian ethnic origin question card before surveying the relative status of ethnic minorities in the labor market.<sup>87</sup> Prior to developing a statistical classification for cultural and ethnic groups, the Australian Bureau of Statistics conducted not only an extensive literature and existing data review, but consulted with ethnic and community groups, as well as agencies which provide and use cultural diversity data.<sup>88</sup>

## 2.3 European law

EU data protection law currently in force is based on the Data Protection Directive, adopted in 1995. The Directive provides protection against abuse of personal data, as defined in Article 2 (a): “personal data’ shall mean any information relating to an identified or identifiable natural person (‘data subject’); an identifiable person is one who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity.”

A proposal for a general data protection regulation (the “Data Protection Package”)<sup>89</sup> was adopted by the European Parliament at first reading on March 12, 2014. It aims at ensuring a consistent level of protection of personal data and equivalent powers for monitoring and ensuring compliance throughout the Union, and repeals the current Data Protection Directive. The proposal prohibits in general the processing of “special categories of personal data,” including data which reveals race or ethnic origin and religion or beliefs, as well as data concerning health or sex life. On the other hand, it provides for an extensive list of exemptions, thereby

85 Jaak Billiet, “Questions about national, subnational and ethnic identity,” in *European Social Survey Core Questionnaire Development* (London: European Social Survey, City University London: 2001), [http://www.europeansocialsurvey.org/docs/methodology/core\\_ess\\_questionnaire/ESS\\_core\\_questionnaire\\_national\\_ethnic\\_identity.pdf](http://www.europeansocialsurvey.org/docs/methodology/core_ess_questionnaire/ESS_core_questionnaire_national_ethnic_identity.pdf).

86 Jürgen H.P. Hoffmeyer-Zlotnik and Uwe Warner, “The Concept of Ethnicity and its Operationalisation in Cross-National Social Surveys,” *Metodološki zvezki*, Vol. 7, no. 2 (2010): 107-132.

87 Interview with Anthony Heath on April 3, 2014, Florence.

88 Australian Bureau of Statistics, “About the Classification” <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/1249.0Main%20Features22011?opendocument&tabname=Summary&prodno=1249.0&issue=2011&num=&view=>

89 European Commission Proposal for a Regulation of the European Parliament and of the Council on the protection of individuals with regard to the processing of personal data and on the free movement of such data (General Data Protection Regulation) COM(2012) 11 final.

underlining that the collection of such data is justifiable in certain, well-defined situations.<sup>90</sup> Although some of these exceptions have been rephrased or clarified in the wording of the proposed regulation compared to that of Directive 95/46/EC, most have remained the same.<sup>91</sup> In addition, Chapter IX of the proposal provides for specific data processing situations, including the processing of personal data in the employment context, the processing and publication of such data for “historical, statistical and scientific research purposes,” and the processing of personal data concerning health for specific purposes including reasons of public interest.<sup>92</sup>

The Racial Equality Directive and the Employment Equality Directive are also relevant when it comes to data collection. In view of the definition of “indirect discrimination” under these antidiscrimination directives, the collection of data in the field of employment, vocational and tertiary education is necessary to enable those who are harmed to challenge discrimination. Under these directives, “indirect discrimination shall be taken to occur where an apparently neutral provision, criterion or practice would put persons of a (protected ground) at a *particular disadvantage compared with* other persons, unless that provision, criterion or practice is objectively justified by a legitimate aim and the means of achieving that aim are appropriate and necessary” (emphasis added).<sup>93</sup> When establishing a claim of indirect discrimination, national evidentiary “rules may provide in particular for indirect discrimination to be established by any means including *on the basis of statistical evidence*” (emphasis added).<sup>94</sup> In addition, and more generally, equality data collection is necessary to effectively implement the antidiscrimination directives, as it constitutes the only reliable means to measure (in)equality, design remedies, and monitor their effectiveness.

The CRPD has been signed and ratified by the EU as well as the Member States under review except Ireland. Its Article 31, titled “Statistics and data collection,” renders disability data collection mandatory with a view to assessing implementation and the adoption of positive action measures based on disability as follows:

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.
3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

90 General Data Protection Regulation, Article 9.

91 See Data Protection Directive, Article 8.

92 See General Data Protection Regulation, Articles 81, 82, and 83.

93 Article 2.2. b of the Racial Equality and Employment Equality Directives.

94 Recital (15) of the Preambles of the Racial Equality and Employment Equality Directives.

### 3. State of the art: A comparative analysis of seven EU Member States<sup>95</sup>

This chapter assesses the legal and policy context at the national level. It focuses on data protection and non-discrimination laws and policies. Despite the common legal background based on the Council of Europe Convention no. 108 and Council Directive 95/46/EC, national traditions, historical events, and societal attitudes have led to significant differences in the legislative and policy frameworks regarding equality data collection of the seven EU Member States under review. However, some similarities can also be discerned, in particular where EU law has had a strong influence on national developments.

The main general findings are the following:

- Despite similar *legislative frameworks* regulating data protection, important differences in *policy approaches* prevail among the countries.
- *The collection of data that reveal ethnic origin and disability is authorized by the legislation* in all seven countries, provided that the legislative safeguards are respected.
- *Specific legislation or policy* regulating the issue of data collection in the field of public education/employment is very rare.

#### 3.1 Legislation and policies: What are the barriers to data collection?

National legislation and policy on data collection need to be assessed in the context of European law and international obligations that define the Member States' duties to prohibit discrimination and promote equality on the one hand, and to protect personal data on the other.

##### 3.1.1 Antidiscrimination legislation and equality duties

The Racial Equality Directive prohibits discrimination on the grounds of race and ethnic origin in several fields including education, while the Employment Equality Directive prohibits discrimination only in the field of employment on the grounds of religion or belief, disability, age, and sexual orientation. In addition to the EU antidiscrimination directives and the Charter of Fundamental Rights of the European Union (which also prohibits discrimination in its Article 21), the countries under review have an obligation to secure the rights contained in the ECHR without discrimination on any ground whatsoever, as stipulated by its Article 14. As provided by Article 2 of Protocol no. 1 to the Convention, this includes the right to education. Among the seven countries under review, however, only Romania has ratified Protocol no. 12 to the Convention, which imposes a general prohibition of discrimination going beyond the rights contained in the Convention.

<sup>95</sup> Please note that this section draws conclusions and comparisons from the reports provided by one independent expert for each selected country.

The seven Member States have all transposed the EU Racial Equality and Employment Equality Directives, in some cases going beyond their scope. In Bulgaria, France, Germany,<sup>96</sup> Hungary, Romania, and Sweden there is one general antidiscrimination act covering all grounds of discrimination and all fields, while in Ireland there is one separate act for the field of employment and one for the other fields covered by the Racial Equality Directive.

In addition to general antidiscrimination legislation, all the selected countries apart from Sweden<sup>97</sup> have adopted separate legislation on the specific ground of disability which includes antidiscrimination provisions, transposing in particular EU law on the duty to provide reasonable accommodation. Such separate disability legislation generally also ensures that the special educational needs of children are met, whether in mainstream education or in special schools.

However, the situation is much more varied when it comes to ethnic origin. None of the selected countries have any ground-specific antidiscrimination legislation on ethnic origin. Nonetheless, some have adopted legislation pursuing other objectives but with a direct impact on antidiscrimination law and policy as regards the ground of ethnic origin. The most interesting examples include the Hungarian legislation protecting and promoting the rights of national minorities, and the specific regulations in Germany which entitle students with a foreign mother tongue to special support in public education.

Significantly, national legislation goes beyond the requirements of EU law, prohibiting discrimination on grounds of disability in the field of education in all the selected countries except one. In Romania, disability is not an explicitly protected ground in the field of education, although the national equality body extends protection to this ground in its practice. In Germany the federal General Act on Equal Treatment only prohibits disability discrimination in private education; however, there are both federal and State constitutional provisions as well as the Berlin School Law prohibiting discrimination on the grounds of disability in public education. In Bulgaria, Hungary, Ireland, and Sweden the general antidiscrimination acts explicitly cover the ground of disability in the field of education.

### *Antidiscrimination clauses in legislation on public education / employment*

All the selected countries have adopted specific legislation on public education/employment. In general, this legislation includes provisions on the schooling of children with special educational needs. Although in most countries either the Constitution or a legal act provides a general clause on equality in education, they do not always include specific provisions prohibiting discrimination on the grounds of disability or race and ethnic origin.<sup>98</sup> In Romania the previous Education Law<sup>99</sup> defined and prohibited segregation in education; these provisions were, however, removed in the new Education Code in force since 2011, which only expressly prohibits discrimination in tertiary education. Thus, there is no clause in the current Romanian Education Code which explicitly prohibits discrimination in primary and

<sup>96</sup> In Germany there are State-specific antidiscrimination acts in addition to the federal antidiscrimination act.

<sup>97</sup> In Sweden, since the entry into force on January 1, 2009 of the Discrimination Act (SFS 2008:567) covering all the grounds protected by the EU antidiscrimination directives, there have no longer been any ground specific acts.

<sup>98</sup> See the table on “Antidiscrimination clauses in public education legislation (employment law for France),” page 32.

<sup>99</sup> Education Law 84 of 1995, published as amended by Law 151/1999, republished in *Monitorul Oficial*, no. 370/August 3, 1999.

secondary education, although “abusive diagnostic assessments” are specifically prohibited. In Sweden, the Education Act includes a prohibition of “insulting treatment” which is defined as a violation of the dignity of a child which does not constitute discrimination under the antidiscrimination law. In Hungary and Ireland there is no specific antidiscrimination clause in the public education legislation. In the field of public employment, the French legislation contains a general antidiscrimination clause where the protected grounds are listed, including both racial and ethnic origin (real or assumed) and disability as well as health status.

#### Antidiscrimination clauses in public education legislation<sup>100</sup> (employment law for France)

	Specific legislation on public education	Antidiscrimination clause in public education	Grounds explicitly covered by the AD clause in public education
<b>Bulgaria</b>	National Education Act (1991)	Prohibition of any “privileges and limitations”	Race/ethnic origin
<b>Germany</b>	Berlin School Act, January 26, 2004	Prohibition of discrimination	Origin + disability
<b>Hungary</b>	Act CXC of 2011 on National Public Education, September 1, 2012 ( <i>entry into force</i> )	N/A	N/A
<b>Ireland</b>	Education Act 1998-2012	N/A	N/A
<b>Romania</b>	Education Code (Law 1/2011), January 5, 2011	No specific antidiscrimination clause BUT express prohibition of discrimination in tertiary education and prohibition of “abusive diagnostic assessment”	Race/ethnic origin (in the express prohibition)
<b>Sweden</b>	Education Act (1985:1100), December 12, 1985 (no longer in force) / Education Act (2010:800), June 23, 2010	No specific antidiscrimination clause BUT prohibition of “insulting treatment” (violation of the dignity of a child that does not constitute discrimination)	N/A
<b>France (public employment)</b>	Law 83-634 on Rights and Obligations of Public Servants, July 13, 1983 (as amended)	Prohibition of any distinction	Race/ethnic origin (real or assumed) + disability (+ health status)

100 Please note that this table only covers antidiscrimination clauses in specific legislation on public education/employment (excluding for instance general antidiscrimination legislation).



*Equality bodies*

The competencies and powers of equality bodies and school inspectorates vary considerably in the different countries examined. In general, it can be said that not many of these authorities have been using their mandates very actively to work against discrimination in public education. An interesting example of an equality body using its competencies in this field is the work done by the Hungarian Equal Treatment Authority, a quasi-judicial body, in several important cases of segregation of Roma children in education as well as inclusive education for children with disabilities. When investigating various cases brought before it, the equality body has, for instance, had ethnic data generated based on the perception of members of the local Roma minority self-Government<sup>101</sup> so as to establish the existence of segregation of Roma children in schools.

*Equality duties and positive action*

The EU antidiscrimination directives permit — but do not impose — positive action. Article 7 of the Employment Equality Directive entitled “Positive action” provides that

1. With a view to ensuring full equality in practice, the principle of equal treatment shall not prevent any Member State from maintaining or adopting specific measures to prevent or compensate for disadvantages linked to any of the grounds referred to in Article 1.
2. With regard to disabled persons, the principle of equal treatment shall be without prejudice to the right of Member States to maintain or adopt provisions on the protection of health and safety at work or to measures aimed at creating or maintaining provisions or facilities for safeguarding or promoting their integration into the working environment.

Article 5 of the Racial Equality Directive entitled “Positive action” stipulates that

With a view to ensuring full equality in practice, the principle of equal treatment shall not prevent any Member State from maintaining or adopting specific measures to prevent or compensate for disadvantages linked to racial or ethnic origin.

On the other hand, Article 2.2 of the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD), a treaty signed and ratified by all EU Member States and invoked in the Preamble of the Racial Equality Directive, makes positive action measures mandatory if the conditions stipulated in ICERD so require. In order to comply with this provision, positive action must be taken. In order to design positive action measures, equality data are needed. Article 2.2 reads as follows:

101 A body elected by local Roma to represent their interests as a national minority, i.e., in the fields of education, culture, etc.

States Parties shall, when the circumstances so warrant, take, in the social, economic, cultural and other fields, special and concrete measures to ensure the adequate development and protection of certain racial groups or individuals belonging to them, for the purpose of guaranteeing them the full and equal enjoyment of human rights and fundamental freedoms. These measures shall in no case entail as a consequence the maintenance of unequal or separate rights for different racial groups after the objectives for which they were taken have been achieved.

Clearly, prior to collecting ethnic data in pursuance of this provision, the discrepancy between Article 5 of the Racial Equality Directive and Article 2.2 ICERD needs to be resolved, as positive action is optional under the former and mandatory under the latter.

Alternatively and additionally, equality data collection may be needed as a means to provide effective, proportionate and dissuasive remedies as required under Article 15 of the Racial Equality Directive and Article 17 of the Employment Equality Directive. This argument has already gained ground in *Horváth and Kiss v. Hungary*, where the European Court of Human Rights found that States have a duty to implement positive action measures to stem longstanding and structural discrimination against Roma children in education.<sup>102</sup> It can also be noted that the Court recognized the special needs of disadvantaged groups such as the Roma already in *D.H. and others v. Czech Republic*.<sup>103</sup>

In the field of employment as regards the ground of disability, Article 5 of the Employment Equality Directive imposes on employers in the EU Member States a duty to provide reasonable accommodation for employees and candidates with disabilities. This duty is phrased as a means to ensure equal treatment, and although EU law per se does not extend it to any fields beyond employment, the CRPD imposes a general obligation on States Parties to “take all appropriate steps to ensure that reasonable accommodation is provided,” (Article 5.3) which is not limited to any specific field.

Equal opportunities planning is the process of designing and implementing positive action, which logically requires data on the target groups. Education stakeholders such as schools themselves or competent ministries/authorities in the selected countries are rarely under the duty to perform any equal opportunities planning, as it is only mandatory in Sweden and Hungary. Equal opportunities planning is implied as a requirement to some extent in Ireland and Germany, and neither imposed by law nor de facto conducted in Romania and Bulgaria. In **Sweden**, all education providers have a duty to draw up a yearly equal treatment plan, including not only measures to promote the equal rights and opportunities of pupils and students, but also measures to prevent and hinder harassment. The legislation does not provide any guidance on how data should be collected for equality plans, and data do not seem to be collected in any generalized way for this purpose. In addition, it appears that neither the equality body nor any

102 *Horváth and Kiss v. Hungary* (2013) 57 EHRR 31, para 104. For a more detailed analysis of the definition of the Roma and mandatory positive action in their regard see: Isabelle Chopin, Uyen Do and Lilla Farkas, *Promoting the implementation of European Union equality and non-discrimination standards in the programming and implementation of structural funds* (Brussels and Budapest: Migration Policy Group, 2013), <http://www.migpolgroup.com/portfolio/promoting-implementation-european-union-equality-non-discrimination-standards-programming-implementation-structural-funds-respect-roma/>, 34-43.

103 *D.H. and others v. the Czech Republic* (2007) 47 EHRR 3, para 207.

other authority inspects the equal treatment plans, nor has such a plan apparently ever been challenged before the competent authority, the Board against Discrimination.

In **Hungary**, the previous Public Education Act provided for a system of incentives where local governments were required to adopt an action plan on equal opportunities in public education as a precondition for participation in national and international tenders allocating resources for the purposes of public education. These plans were to facilitate the integration and access to education of “multiply disadvantaged”<sup>104</sup> (mostly Roma) children, and to counter discrimination in education. The government provided guidance and samples for the drafting of these equality plans, including an instruction to collect data on the number of socially and multiply disadvantaged children, and on children with special educational needs. The guidance also indicated that the local Roma self-governments should be involved in the development of any antisegregation measures in the equality plans. As in Sweden, there does not seem to have been any structured assessment of the action plans or of their implementation, although under this legislation funding for certain projects was only granted to local governments who fulfilled this obligation. When the project was granted the action plan became a contractual obligation, but there does not appear to have been any extensive monitoring of the fulfilment of these obligations either. This provision was removed when the new National Education Act was adopted in 2011, although the majority of equality plans remain in force. In addition, local governments are under a duty to provide other, more general, equality planning.

In **Ireland**, the Education Act sets out several general duties, including a requirement for schools to use their available resources in a way so as to ensure that the educational needs of all students, including those with special educational needs, are identified and provided for. The Act also makes it obligatory for school boards to provide school plans, stating the school’s objectives in terms of equality of access to and participation in the school, and the measures which the school proposes to take to achieve those objectives. The Education for Persons with Special Educational Needs Act also sets out specific requirements, including the provision of education plans and reviews, although these cannot be said to constitute concrete legal duties. Similarly, legal duties are lacking in **German** legislation. Here, no strict legal duty to provide equal opportunities planning with measurable results or set criteria exists. Nonetheless, some duties are imposed to guarantee equality in education. These include a requirement on schools to ensure that pupils with learning difficulties as well as those who do not have German as a mother tongue receive support and additional measures that they need.

In **France** in the field of public employment, no duty is imposed on public employers to carry out any strict equality planning although some public undertakings have adopted formal commitments called “diversity charters.” The Law on Equal Rights and Opportunities, Participation and Citizenship of People with Disabilities<sup>105</sup> must also be mentioned in this regard, as it imposes a quota of 6 percent of employees with disabilities applicable to all public and private sector companies with more than 20 employees. All employers concerned are under

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104 The category of “multiply disadvantaged” children is defined in the Hungarian Act on Child Protection and Guardianship Administration. It covers children who can benefit from the integration program: namely, children whose parents attended only elementary school and whose family is eligible for supplementary family allowance (i.e., they come from an economically disadvantaged environment) or those who have special needs according to the head of the school. Pupils who live in the care of the state also belong to this category.

105 Law 2005-102 of February 11, 2005.

an obligation to provide information annually on the number of employees with disabilities, and to pay a fine if the quota is not achieved.

### 3.1.2 Data protection legislation

#### Overview

The EU Data Protection Directive was adopted with the aim of protecting individuals' right to privacy with regard to the processing and free movement of their personal data. Its Article 2(a) defines "personal data" as being "any information relating to an identified or identifiable natural person." The Directive covers only data that is processed by automatic means or that is "intended to form part of a filing system," and excludes from its scope data that are processed by a natural person for purely personal or household purposes (Article 3). It sets out a series of minimum principles for the lawful processing of personal data and provides for a general prohibition of processing of special categories of personal data, defined as "personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and ... data concerning health or sex life." In its Articles 8.2 to 8.4 it lists situations where the processing of special data is exempt from the general prohibition.

All of the selected States have adopted specific legislation on the protection of personal data, although in some countries there are specificities. For instance, in Ireland there are several pieces of legislation<sup>106</sup> with separate fields of application, such as an act on the collection of data for statistical purposes, and in Romania there is a specific act regulating the protection of privacy in electronic communications. Germany has both federal and State data protection acts, as well as several regulations on data protection in specific fields.<sup>107</sup> As public education is mainly a competence of the *Länder*, the most relevant act for this research is the Berlin School Data Decree,<sup>108</sup> which regulates the collection of data by schools and by the Senate Office for Education at the State level, on the basis of the Berlin School Law.<sup>109</sup> However, the Berlin Data Protection Act is subsidiary to other provisions authorizing data collection and processing, in so far as they are stricter — i.e., they provide for stronger protection of personal data and less extensive exceptions to the prohibition of collecting and processing "sensitive" data. Thus, in the field of public education, the Berlin Data Protection Act ensures minimal protection of personal data while the Berlin School Data Decree contains more specific and restrictive provisions as regards data collection in this field.

All the countries have transposed Directive 95/46/EC, defining the concept of personal data by following more or less exactly the wording of the Directive. Thus, for instance in Romania personal data are defined as "any information referring to a natural person, identified or identifiable," while Swedish law covers any kind of information that directly or indirectly may be referable to a person who is alive. These definitions are comparable for the purposes of this research, as are the general scopes of application of data protection legislations. These cover data that are processed automatically or manually but exclude from their scope natural

106 The Statistics Act 1993, the Data Protection Acts 1998 & 2003 and the Freedom of Information Acts 1997 & 2003.

107 See, for instance, the Act on Public Servants of the State of Berlin (*Landesbeamtengesetz*).

108 *Schuldatenverordnung* of October 13, 1994, last amended by decree of September 5, 2010 (published in GVBl. 2010, S. 448).

109 Please note that the State of Berlin was selected as an illustration of legislation, policy and practices on the State (*Land*) level in Germany, where public education does not fall under the scope of federal competencies.

persons processing data exclusively for their own personal purposes. In several countries data which are processed exclusively for artistic, journalistic or literary purposes are excluded from the scope of the data protection legislation. Transposing the Directive, each country has established a public authority vested with the responsibility to monitor the application on the national level of data protection legislation.

Processing of personal data is authorized in all the selected countries when the person who is identified or identifiable by the data concerned has given his or her express and informed consent to the processing, and in a certain number of other situations. The national provisions regulating these situations also reflect more or less the provisions of the Directive, and generally include situations where the processing is necessary:

in order to fulfill the obligations of a contract with the person concerned;  
for the data controller to comply with legal obligations;  
to protect vital interests of the person concerned;  
to perform a task of public interest.

### *Sensitive personal data*

Authorized data collection is, however, further restricted where categories of data considered as “sensitive” or “special” are concerned. These categories are generally defined in terms of the type of information they reveal, such as political opinions, religious beliefs and sexual orientation. In all the selected countries, data revealing racial or ethnic origin and disability is considered as “sensitive,” although it is sometimes categorized differently. For instance, disability generally falls under the category of data that reveal health status.

**GENERAL PRINCIPLE:**  
*prohibition of processing sensitive data.*  
*Exceptions and exclusions from the scope of the prohibition*

### Categories of sensitive data in national law

	Categories of “sensitive” / “special” data	Relevant legal provision
<b>Bulgaria</b>	Data revealing <i>racial or ethnic origin</i> ; political, religious or philosophical convictions, membership of political parties and organizations, associations having religious, philosophical, political or trade union goals; data referring to <i>health</i> , sexual orientation or human genetics.	Personal Data Protection Act, Article 5.
<b>Germany</b>	Data on <i>racial and ethnic origin</i> , political opinion, religious and philosophical beliefs, trade union membership, <i>health</i> and sexuality.	Federal Data Protection Act, Section 3, para. 9.

	Categories of “sensitive” / “special” data	Relevant legal provision
<b>Hungary</b>	Data revealing <b>racial origin or nationality</b> , political opinions and any affiliation with political parties, religious or philosophical beliefs and trade union membership; data concerning sex life, <b>health</b> , pathological addictions or criminal records.	Data Protection Act, Article 3, para. 3.
<b>Ireland</b>	Personal data as to <b>racial or ethnic origin</b> , political opinions or religious or philosophical beliefs, trade union membership, <b>physical or mental health or condition</b> or sexual life, commission or alleged commission of any offense, any proceedings for an offense committed or alleged to have been committed, the disposal of such proceedings or the sentence of any court in such proceedings.	Data Protection Acts 1998 and 2003, Section 1.
<b>Romania</b>	Data regarding <b>racial or ethnic origin</b> , political, religious or philosophical or similar beliefs, trade union membership, <b>health status</b> or sexual life.	Law 677/2001, Article 7(i).
<b>Sweden</b>	Data revealing <b>race or ethnic origin</b> , political opinion, religious or philosophical belief, membership of a trade union and <b>health</b> and sex life.	Personal Data Act, Section 13.
<b>France</b>	Data revealing <b>racial or ethnic origin</b> ; political, philosophical or religious opinion; trade union membership, or relating to <b>health</b> or sexual life.	Law on Information Technologies and Freedoms, Article 8

In the State of Berlin, the Berlin School Law defines sensitive data, while the Berlin School Data Decree specifies the additional safeguards for a list of specific categories of data, including data on nationality, non-German mother tongue and language spoken in the family, as well as special educational needs. These specific categories of data may only be processed in a nonpersonalized, aggregate form while other types of data only need to be pseudonymized.

### *Prohibition and exceptions*

The general principle in the selected countries is the prohibition of processing of “sensitive” data, although there are both exemptions to this prohibition and situations which are excluded from its scope. Thus, the opportunity for such data collection exists in a range of specific situations. The exemptions to the prohibition of data collection as regards sensitive data are more restrictive than the situations where the processing of data is authorized in general, and they extensively reflect the provisions of the Directive.

Articles 8.2 to 8.4 of the Data Protection Directive:

2. [The prohibition of processing special categories of data] shall not apply where:
  - (a) the data subject has given his explicit consent to the processing of those data, except where the laws of the Member State provide that the prohibition referred to in paragraph 1 may not be lifted by the data subject's giving his consent; or
  - (b) processing is necessary for the purposes of carrying out the obligations and specific rights of the controller in the field of employment law in so far as it is authorized by national law providing for adequate safeguards; or
  - (c) processing is necessary to protect the vital interests of the data subject or of another person where the data subject is physically or legally incapable of giving his consent; or
  - (d) processing is carried out in the course of its legitimate activities with appropriate guarantees by a foundation, association or any other non-profit-seeking body with a political, philosophical, religious or trade-union aim and on condition that the processing relates solely to the members of the body or to persons who have regular contact with it in connection with its purposes and that the data are not disclosed to a third party without the consent of the data subjects; or
  - (e) the processing relates to data which are manifestly made public by the data subject or is necessary for the establishment, exercise or defense of legal claims.
3. Paragraph 1 shall not apply where processing of the data is required for the purposes of preventive medicine, medical diagnosis, the provision of care or treatment or the management of health-care services, and where those data are processed by a health professional subject under national law or rules established by national competent bodies to the obligation of professional secrecy or by another person also subject to an equivalent obligation of secrecy.
4. Subject to the provision of suitable safeguards, Member States may, for reasons of substantial public interest, lay down exemptions in addition to those laid down in paragraph 2 either by national law or by decision of the supervisory authority.

In some of the countries under review the data protection legislation provides for more or less all of the possible exceptions listed by the Directive, while others such as Bulgaria and Hungary grant quite restrictive exceptions.<sup>110</sup>

<sup>110</sup> See table "Exceptions to the prohibition of collecting sensitive personal data," page 41.

While some of these exemptions are fairly precise and only cover very specific situations, others offer some margin of appreciation to lawmakers or other national authorities. These provisions are generally based on Article 8.4 of Directive 95/46/EC, which gives the national legislator the opportunity of adopting legislation that allows the processing of sensitive personal data where the protection of a “substantial public interest” is in question. One illustration of such an exemption can be found in Section 20 of the Swedish Personal Data Act, which allows the Government or the Data Inspection Board to issue further exemptions from the prohibition on the processing of personal sensitive data. However, no such additional exceptions have been issued. The French data protection act also establishes a general exemption for any data processing which is justified by the public interest and has been duly authorized by the data protection authority, the CNIL. The data collection process must be approved by the CNIL prior to its implementation according to the following standards: the express consent of data subjects has to be ensured; the data collection must have a legitimate objective; and anonymity must be preserved, a condition which has implications for methodology, access to the files and their destruction. In this regard it has to be noted, however, that a legislative bill adopted by the French Parliament in 2007 — which had been examined and authorized by the data protection authority – to allow the collection of “ethnic data” for the purpose of measuring diversity, discrimination and integration, was strongly criticized by antidiscrimination NGOs, and finally struck down by the Constitutional Council.<sup>111</sup>

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111 Constitutional Council, Decision no. 2007-557 DC of November 15, 2007. However, the Constitutional Council only examined the provisions on ethnic data collection from a purely procedural perspective, and struck them down only because they were the result of an amendment that had no link to the rest of the law.



## Exceptions to the prohibition of processing sensitive personal data

	Consent	Employment	Health/life	Public	Members	Legal claim	Medicine	Public interest – Other
<b>BG</b>	X	X	X		X			
<b>FR</b>	X		X	X	X	X	X	<ul style="list-style-type: none"> <li>• Statistical processing by the INSEE (the National Institute of Statistics and Economic Studies).</li> <li>• When justified by the public interest, authorized by the CNIL.</li> <li>• Necessary for medical research.</li> </ul>
<b>DE</b>	X		X	X		X		<ul style="list-style-type: none"> <li>• Scientific research if scientific interest outweighs the data subject's interest in the protection of their data.</li> </ul>
<b>HU</b>	X							<ul style="list-style-type: none"> <li>• Implementation of international agreements promulgated by acts.</li> <li>• Prescribed by law for the enforcement of fundamental rights.</li> <li>• National security / defense or prevention / prosecution of criminal activities.</li> <li>• Necessary for the performance of a task carried out in the public interest.</li> </ul>
<b>IE</b>	X	X	X	X	X	X	X	<ul style="list-style-type: none"> <li>• Statistical compilation and analysis purposes.</li> <li>• Political parties or candidates for electoral purposes / political opinions.</li> <li>• Authorized by regulations made by the Minister for Justice and Equality.</li> <li>• Necessary to collect taxes / revenue.</li> </ul>
<b>RO</b>	X	X	X	X	X	X	X	<ul style="list-style-type: none"> <li>• Express legal provision to protect an important public interest.</li> </ul>
<b>SE</b>	X	X	X	X	X	X	X	<ul style="list-style-type: none"> <li>• Research and statistics for societal purposes, when authorized by the Central Ethical Review Board.</li> <li>• Statistical purposes as required by the Official Statistics Ordinance.</li> <li>• the Government or a public authority may issue further exemptions.</li> </ul>

**Consent:** Sensitive data may be collected when the data subject has given his/her informed consent.

**Employment:** Sensitive data may be collected when it is necessary for an employer to fulfill his/her/its obligations by virtue of employment legislation.

**Health/Life:** Sensitive data may be collected when it is necessary for the health of the data subject and it is impossible to obtain his/her consent.

**Public:** Sensitive data may be collected when the data subject has made the data public him/herself.

**Members:** Sensitive data may be collected by associations or organizations regarding its members.

**Legal claims:** Sensitive data may be collected when it is necessary to establish, exercise or defend legal claims before a court of law.

**Medicine:** Sensitive data may be collected when it is necessary for the purposes of preventive medicine, medical diagnosis, care/treatment or health management.

**Public interest/other:** Sensitive data may be collected in other situations, as provided for by law, when required for reasons of substantial public interest.

In addition to the general provisions on situations that are exempt from the prohibition on processing of sensitive data, there are specific separate regulations relating to data collection and processing for statistical purposes in all of the examined countries except France. There is no such separate act in France, but the general data protection act grants an exception to the prohibition on the collection of sensitive data for statistical purposes when the stipulated safeguards are respected.<sup>112</sup> In Germany the specific statistics acts on both federal and State level fail to mention special or sensitive data in any way, although the provisions on the collection of sensitive data in the general data protection acts also apply to statistics.<sup>113</sup>

#### *Access to information law and transparency duties*

In all the countries researched, the right of individuals to access information available to public authorities is also regulated, either by the data protection legislation or by specific complementary acts, such as the Bulgarian Access to Public Information Act<sup>114</sup> or the Irish Freedom of Information Act.<sup>115</sup> Such regulations have an additional impact on issues surrounding the collection of data in public education. However, none of the selected countries have included provisions dealing particularly with the question of access to information in the specific field of public education, although quite a lot of data are collected. In Germany, on the level of the *Länder*, the Berlin School Law explicitly grants pupils the right to access information contained in the Berlin Freedom of Information Act.<sup>116</sup> A debate has taken place in the State Parliament regarding the age from which pupils should be able to exercise this right without the consent of their legal guardians.

Although the field of public education falls under the scope of access to information legislation in all the selected countries, in Ireland the access to information acts apply to government departments and other authorities responsible for education but not to the schools themselves. In France, public employers fall directly under the provisions on access to information in the data protection act, to the extent to which they collect and process data.

112 *Loi informatique et libertés*, Article 8.2, 7°.

113 *Bundesstatistikgesetz* of January 22, 1987 (published as BGBl. I S. 462, 565), last amended by Art. 3 Law of September 7, 2007 (published as BGBl. I S. 2246); *Landesstatistikgesetz* of December 9, 1992 (published as GVBl. 1992, S. 365), last amended by Art. 2 of Law of March 30, 2006 (published as GVBl. 2006, S. 300).

114 Bulgarian Access to Public Information Act 2000, published in State Gazette 55 of July 7, 2000.

115 Irish Freedom of Information Act 1997 and Freedom of Information (Amendment) Act 2003.

116 As previously noted, the State of Berlin was chosen as an illustration of legislation, policy and practice on State level in Germany, where the field of public education does not fall under federal competencies.

### 3.1.3 Data collection policy

Policy measures, strategies adopted by the States or state authorities, research papers, surveys and other publications have covered the issue of equality data collection to a greatly varying degree in the countries examined by this report. In general, beyond the adoption of legislative measures necessary for the implementation of the Data Protection Directive, the level of policy activity in most of the States under review is comparatively low and receives very little attention. In addition to other policy measures or strategies, all seven countries have adopted National Roma Integration Strategies within the EU framework, yet these strategies generally fail to raise the issue of data collection for the purpose of monitoring their effectiveness.<sup>117</sup>

In Ireland, however, extensive public policy measures and incentives have been adopted with the specific aim of reinforcing the legitimacy of equality data collection. These measures include a general, overarching social policy framework agreement negotiated by the Government, trade unions, employers' and farming organizations as well as the community and the voluntary sector.<sup>118</sup> This agreement includes both a specific short-term commitment to strengthen and develop baseline data/information sources in education and training, and a more general commitment to a new National Data Strategy to "support the planning and delivery of policy and services in relation to early childhood care and education and school age childcare." The National Statistics Board has also adopted a Strategy for Statistics 2009-2014 that includes a commitment to fill certain "critical data gaps," including integrated pupil data, as well as a recommendation for the Department of Education and Science to give high priority to the development of a Learner Database to monitor progress through the education system. In 2008, the Department for Education and Science published its Data Strategy 2008-2010,<sup>119</sup> also setting up an implementation group. This strategy was highly relevant, although resource constraints made it impossible to adopt a subsequent strategy when it had run its course. Ironically, despite the development of such relevant policies and strategies, there seems to be a comparatively low level of debate among civil society organizations, private research initiatives and/or reports on this issue in Ireland.<sup>120</sup>

In most of the other countries public authorities have adopted plans or strategies on equality and inclusion/integration in the relevant fields. These include, for instance, the Bulgarian national strategies for equal opportunities of disabled people and for the integration of the Roma; the German action plans both at federal and State level on integration and the implementation of the CRPD; and the Hungarian National Strategy on Disability Affairs. None of these, however, explore the specific issue of data collection for integration or antidiscrimination purposes, although some incidentally mention that the lack of available and reliable data is problematic for the development of such plans and strategies. The Bulgarian expert reported that the

117 The issue of data collection was raised by the European Council in its Recommendation of 9 December 2013 on effective Roma integration measures in the Member States (2013/C 378/01), as a recommended structural measure to be put in place for the effective realization of strategies' objectives.

118 Department of the Taoiseach, *Towards 2016 – Ten Year Framework Social Partnership Agreement* (Dublin: Stationery Office, 2006), [http://www.taoiseach.gov.ie/attached\\_files/Pdf%20files/Towards2016PartnershipAgreement.pdf](http://www.taoiseach.gov.ie/attached_files/Pdf%20files/Towards2016PartnershipAgreement.pdf).

119 Department of Education and Science, *Data Strategy 2008-2010*, <http://www.education.ie/en/Publications/Statistics/Data-Strategy-2008-2010.pdf>.

120 The Irish NGO Pavee Point has, however, been active in raising the issue of equality data, particularly with regard to Travelers.

national strategies seem to be based on perceptions rather than on actual data on persons with disabilities and persons belonging to ethnic minorities, which gives rise to grave concerns.

In Sweden no extensive policy measures have been adopted by the State or public authorities in the field of public education, whether in relation to the ground of ethnic origin or disability. However, the Swedish Government showed some awareness of the issue of equality data collection when requesting the Equality Ombudsman to commission a report assessing possible avenues for amending legislation and/or data collection practice in relation to the national annual survey on living conditions. The report published in 2012 entitled *The role of statistics in combating discrimination*<sup>121</sup> examines the legal, political and moral/ethical possibilities of introducing other characteristics such as ethnic origin, religious beliefs and disability into the annual survey on living conditions, which already covers “objective” personal characteristics (age and gender). The author recommends that questions which reveal ethnic origin, disability, sexual orientation and religious beliefs be included in the survey questionnaire. This amendment would be legally possible based on the exception under Article 8.4 of Directive 95/46 and the national implementing legislation. The report’s recommendations are based on extensive consultations with civil society organizations representing the different groups concerned by the research, and the results of these consultations are publicly available.<sup>122</sup> This report may have interesting consequences in the near future for practice and legislation in Sweden as regards the collection of sensitive data, although the Government has expressed its reluctance to pursue the recommendations. Apart from this one report, however, the level of research seems to be comparatively low in Sweden as well.

In Romania, there have been no public policy measures or private initiatives such as studies, surveys, and other publications by civil society organizations or independent researchers that are relevant to the issue of equality data collection. In Bulgaria civil society organizations as well as the equality body and the National Ombudsman are reportedly quite active in the debate on this issue, which was also discussed during the recent elaboration of the National Strategy for the Roma Minority (2012-2020), and some articles have been published, in particular by the Access to Information Foundation. However, no public policy measures have been adopted.

In contrast, several relevant reports and studies have been published in recent years both in Germany and Hungary. These include a German feasibility study published in 2010 entitled *Standardized data collection to prove discrimination? — Survey and outlook*,<sup>123</sup> providing recommendations for the development of data collection on discrimination and of representative surveys to identify vulnerable groups. As regards disability, the report *Human rights-based data collection — key to good disability policy. Requirements of article 31 of the UNCRPD*<sup>124</sup> published by the German national CRPD monitoring body in 2012 and

121 Yamam Al-Zubaidi, *Statistikens roll i arbetet mot diskriminering (The role of statistics in combating discrimination)* (Stockholm: Diskrimineringsombudsmannen (DO), 2012).

122 Website of the Equality Ombudsman: [http://www.do.se/Documents/rapporter/Bilagor\\_statistikens%20roll.pdf](http://www.do.se/Documents/rapporter/Bilagor_statistikens%20roll.pdf).

123 Mario Peucker, Claudia Lechner, *Standardisierte Datenerhebung zum Nachweis von Diskriminierung!? – Bestandsaufnahme und Ausblick* (Berlin: Antidiskriminierungsstelle des Bundes, 2010).

124 Marianne Hirschberg, *Human rights-based data collection – key to good disability policy. Requirements of article 31 of the UN CRPD* (Berlin: Deutsches Institut für Menschenrechte, 2012).

the Hungarian alternative CRPD report *Disability rights or disabling rights?*<sup>125</sup> both seem particularly relevant, as they include concrete recommendations on the collection of disability data. These recommendations include the establishment of an independent representative survey on the living conditions of people with disabilities, the testing and development both by the Government and through scientific research of human rights based indicators as well as the recommendation that substantial negotiations be conducted between representative organizations and national statistical offices in order to adopt a program to foster the collection of disability data. In Hungary, there are reports and strategies highlighting the lack of reliable data both regarding ethnic minorities and people with disabilities, including most importantly a joint recommendation on processing ethnic data published in 2009 by the Parliamentary Commissioners (Ombudsmen) for the Rights of National and Ethnic Minorities and for Data Protection.<sup>126</sup> This report discussed at length the differences in legitimacy and methodology of equality data collection with regard to the objectives of protecting personal data and ensuring minority rights. Academics and leading human rights NGOs participated subsequently in a follow-up debate on this joint recommendation.<sup>127</sup>

Finally, in France there have been several reports and other initiatives of relevance in recent years, including reports published by the national demographic research institute INED (*Institut national d'études démographiques*), identifying acceptable ways of collecting ethnic data.<sup>128</sup> A highly topical handbook on data collection in the workplace for employers was also published jointly by the national equality body and the data protection authority in 2012.<sup>129</sup> These guidelines, however, highlight the strict legislative boundaries imposed on the collection of data that reveal disability/health status and racial or ethnic origin.

In addition, international and/or national organizations have in recent years provided reports regarding each of the selected countries regretting the lack of available equality data or presenting this lack of data as having a deterrent effect on policy making in the field of antidiscrimination.

### 3.2 Categories, proxies, and sources: What are the practices of data collection?

This section provides an overview of the categories used for data collection in the seven countries under review and of the sources of data available in these countries. The general categories, methodologies and sources used are explained and selected national practices are further analyzed.

125 Hungarian Disability Caucus, *Disability rights or disabling rights?* (Budapest: Hungarian Association of the Deaf and Hard of Hearing (SINOSZ), Mental Disability Advocacy Centre and National Council of Disabled Persons' Organizations (FESZT): 2010). Available in English at: <http://mdac.info/en/resources/disability-rights-or-disabling-rights-crpd-alternative-report>.

126 Parliamentary Commissioner for the Rights of National and Ethnic Minorities and the Parliamentary Commissioner for Data Protection and Freedom of Information, *Report on the conclusions of a study on the processing of ethnically disaggregated data* (Budapest: 2009). Available in Hungarian at: <http://kisebbssegiombudsman.hu/data/files/158627216.pdf>.

127 See section 4.1 of this report for further detail.

128 See for instance Patrick Simon and Martin Clément, *Rapport de l'enquête 'mesure de la diversité'. Une enquête expérimentale pour caractériser l'origine* (Document de travail no. 136, Paris: INED, 2006), [https://www.ined.fr/fichier/s\\_rubrique/19489/139.fr.pdf](https://www.ined.fr/fichier/s_rubrique/19489/139.fr.pdf).

129 Défenseur des droits et Commission Nationale de l'Informatique et des Libertés (CNIL), *Mesurer pour progresser vers l'égalité des chances* (Paris: CNIL, 2012).

The main general findings are the following:

- Ethnic and disability data are collected in all the selected countries.
- Data are collected either on the basis of a set legal framework not always respecting the applicable safeguards under the active control of the national data protection authority or on an ad hoc, informal basis without respecting the safeguards.
- Data on ethnic origin are collected to a great extent on the basis of proxies whose usefulness is debated by minority communities.
- Data on ethnic origin are not collected based on self-identification, and the necessary safeguards are often not respected.
- As a general rule, disability data are collected based on third-party identification, using disability/ability based categories, where the disability is evaluated by special educational needs commissions or medical experts.

### 3.2.1 Categories and proxies used in data collection and their limits

In the selected countries data signifying ethnic origin and disability are gathered in the relevant fields. However, as a general rule, these data are not publicly available, reliable, objective and comparable or used effectively to inform public policy. It is also questionable whether the types of data collected through these practices correspond to the objective of monitoring progress towards equality in the relevant fields. In addition, while some data collection practices are stipulated by law and regulated by a clear legal framework, others appear to lack any clear legal or regulatory framework, thereby giving ground to suspicions of illegal data collection practices.

#### *Categories of ethnic origin*

In the field of education data based on ethnic categories is only collected in Ireland,<sup>130</sup> while in France no data are collected based on ethnic categories in the field of public employment. Census data are available on ethnic origin in Bulgaria, Hungary, Ireland, and Romania. The three new Member States have designed ethnic categories in the census based on their laws on ethnic minority rights. In France, Germany and Sweden no data are collected on ethnic categories. In Ireland, the Department of Education started in 2014 to collect data in schools from parents regarding the ethnicity and cultural background of their children. The questionnaires include the following categories: White Irish; Irish Traveler; Roma; Any other white background; Black African; Any other Black background; Chinese; Any other Asian background; Other including mixed background. Parents are informed that these data are collected on a voluntary basis and that it is therefore not mandatory to provide this information.

Inroads into formulating self-identification question sets for ethnic origin have been made in Sweden and Hungary. The following factors constitute the bottom line for developing categories and self-identification questions for ethnic origin: (i) proxies based on foreign background are

<sup>130</sup> In Romania, however, data is collected and used on the number of university slots reserved for Roma. Although this constitutes a category of ethnic origin it is neither systematic nor all-encompassing as it only covers one specific ethnic origin (Roma) and does not respect the necessary safeguards.

problematic; (ii) ethnic categories need to be established through consultation; (iii) question sets need to include questions on discrimination experiences (possibly based on “auto-hetero perception”); and (iv) further national level research and consultation is needed to map the social stratification of ethnic minority groups including the Roma.

Ethnic categories are more country specific and as the experience of countries using such categories more or less successfully shows,<sup>131</sup> they are best formulated on the basis of consultation with minority groups. Alternatively, categories may also be defined by the persons surveyed, but that may pose additional methodological and technical challenges. Focusing only on geographic origin does not yield satisfactory results.

Discrimination appears to be a feature of ethnic minority life in Europe. Collecting data about experiences of discrimination is also useful if there is a need to capture those who — for various reasons — do not wish to or do not identify as members of an ethnic minority but are perceived as such by others. The French *Trajectoires et origines* survey is an example of good practice when measuring the perception of discrimination by racial and ethnic minorities.<sup>132</sup>

The categories and proxies used for ethnic census data collection have been assessed by Simon<sup>133</sup> for the Council of Europe and by Makkonen<sup>134</sup> for the European Union. However, the process of standardization has yet to take place at the regional, the EU or the international level.<sup>135</sup> Categories should also reflect the level of integration and offer the choice of mixed or multiple ethnic identities, as well as options for self-definition under given categories. As Simon recalls, ethnic origin may be defined in national law by reference to minority traditions, culture, shared history and language. Alternatively, national law may list “recognized” ethnic minorities.

The European Court of Human Rights (ECtHR) has identified the Roma not only as an ethnic minority but also as a socially disadvantaged group with particular needs. This approach was further developed in *Yordanova and Others v. Bulgaria*, where the Court recognized the “underprivileged status of the applicants’ group” in relation to housing (emphasis added).<sup>136</sup> At the EU level, Roma are the only ethnic group that is specifically targeted by policy measures.

The need to reclassify ethnic origin question sets and categories has to some extent been addressed in ESS core questions and FRA discrimination surveys.<sup>137</sup> A basic scheme for ethnic

131 European Commission, *Comparative study on the collection of data to measure the extent and impact of discrimination within the United States, Canada, Australia, the United Kingdom and the Netherlands*.

132 TeO, “Trajectories and origins,” is the latest major study conducted by the National Institute of Demographic Studies (INED) and the National Institute for Statistical Studies (INSEE) on the topic. All publications based on those data (collected at the end of 2008) are listed on the study website: [http://teo\\_english.site.ined.fr/](http://teo_english.site.ined.fr/).

133 Simon, *Ethnic statistics and data protection in the Council of Europe countries*.

134 Makkonen, *Measuring Discrimination: Data Collection and EU Equality Law*.

135 UNECE, *Conference of European Statisticians Recommendations for the 2010 censuses of population and housing* (New York and Geneva: United Nations, 2010), [http://www.unece.org/fileadmin/DAM/stats/publications/CES\\_2010\\_Census\\_Recommendations\\_English.pdf](http://www.unece.org/fileadmin/DAM/stats/publications/CES_2010_Census_Recommendations_English.pdf).

136 *Yordanova and Others v. Bulgaria*, App. no. 25446/06, (ECHR April 24, 2012), paras 129-133.

137 European Social Survey, *Source Questionnaire Amendment 01 (Round 6, 2012/13)* (London: Centre for Comparative Social Surveys, City University London, 2012). [http://www.europeansocialsurvey.org/docs/round6/fieldwork/source/ESS6\\_source\\_main\\_questionnaire.pdf](http://www.europeansocialsurvey.org/docs/round6/fieldwork/source/ESS6_source_main_questionnaire.pdf), questions C9 on religion and C16-C28 on ethnic and geographic origin.

origin question sets based on these initiatives and the Australian model may be desirable.<sup>138</sup> The questions that are currently in use in Europe have the potential to be developed. They need to capture the richness and perhaps the most prevalent elements of ethnic origin, such as minority religion, language, cultural, family and social customs (food, music and art), historical links and national/ethnic aspirations. They need to portray minorities as being multi- as opposed to one-dimensional, as if an ethnic minority's identity could be reduced to the traditions that it cultivates. Thus, they need to portray a living and dynamic minority reality with all its complexities. The questions currently in use could be revised to better explain what sets an ethnic minority apart from the ethnic majority. They could be developed into tools measuring similarities among ethnic groups who originate from a geographic region. Last but not least, they need to canvass experiences of discrimination based on real or perceived ethnic origin, because such experiences can potentially identify individuals whose ties to ethnic cultures are not strong at the time of the survey but who, regardless of their internal perception, are considered by others as having a minority ethnic background.<sup>139</sup>

### *Proxies for ethnic origin*

Proxy data on ethnic origin is collected across Member States, some of which are not considered sensitive data, while other data — such as data on non-native speakers of German in Germany — are. The proxies used for ethnic origin vary between the countries and do not always serve the purpose of monitoring discrimination or the development of effective antidiscrimination legislation and policy. The proxies for ethnic origin used in the selected countries in the field of education include: nationality; national origin or background (nationality of parents or grandparents); mother tongue or language predominantly spoken in the family; “migration background”; “multiple disadvantage”; and participation in minority education.

In France, the only proxy used in official statistics for ethnic origin in the field of public employment is nationality, although some surveys and other initiatives have attempted to collect data on the basis of other proxies, such as nationality at birth or nationality of parents, language spoken at home and names. In the opinion poll on perceptions of discrimination commissioned by the equality body and the International Labour Organization (ILO), four criteria relate to race: “Traveler community,” “foreigner,” “French of foreign origin” and “French from overseas French territories” (mainly from the Caribbean).

In Germany, official education statistics used to differentiate between German and non-German students. In 2003 the state ministers of education decided to collect data in the future on the basis of students’ “migration background.” Implementation is under way, with the criteria used to establish migration background varying across the *Länder*. They include whether a language other than German is predominantly spoken in the family, non-German nationality and birth abroad as well as cultural background.

<sup>138</sup> For the Australian model, see Australian Bureau of Statistics, “About the Classification.”

<sup>139</sup> It should be considered whether the geographical subgroups created by the FRA and used for its EU-MIDIS survey (see footnote 75 above), could be used generally for ethnic data collection in Europe. For this purpose the subgroups would have to be validated through consultation with the minorities concerned.



In Romania, ethnic data collection in public education is informal and incomplete, and is based on the number of children studying Romanës, or self-identification when seeking access to affirmative measures such as the special places in schools and universities reserved for Roma students or scholarships for Roma pupils.

In Sweden, the only data available revealing ethnic origin in public education is data on “foreign background” (birth abroad of the data subjects and/or of their parent[s]), which is not considered sensitive. In addition, the Swedish National Agency for Education collects and provides data on the segregated schools available for children whose parents self-identify as Sámi (“*sameskola*”).

Proxies may be useful where the data collection is performed in a consistent manner, using an efficient methodology and reliable, objective sources. However, none of the proxies used in practice in these countries can be said to fully reflect ethnic origin as a protected ground in antidiscrimination legislation. Given that ethnic data can be collected under the European data protection regime, the use of proxies does not seem necessary. Proxies are admittedly not the best solution. Moreover, they disempower ethnic minorities and question their right to self-identification. Given the potential for stigmatization, it is advisable that their use be discontinued.

The following table shows the proxies deployed in practice in relation to ethnic origin in the seven Member States under review.

Proxies for ethnic origin used in practice<sup>140</sup>

Category	Bulgaria	Germany	Hungary	Ireland	Romania	Sweden	France
<b>Non-native /minority mother tongue</b>	X	X	X				
<b>Minority classes / schools</b>				X	X	X	
<b>(Socio-)Cultural background</b>		X	X				
<b>Income and level of education combined</b>			X			X	
<b>Foreign born</b>	X	X				X	X
<b>Language spoken at home</b>		X					X
<b>Migration background</b>		X					X
<b>Residence in segregated settlement</b>			Litigation				
<b>Surname</b>		X	Litigation				
<b>Christian name</b>			Ombudsmen				
<b>Known to minority leader as minority member</b>			Litigation		X		
<b>Skin color</b>			Litigation / Ombudsmen				
<b>Nationality</b>		X		X	X	X	X

None of the proxies used in the countries fully reflects ethnic origin as a protected ground in antidiscrimination legislation

This situation does not accord with the Data Protection Directive and in fact the proxies used raise serious doubts in terms of their compliance with its provisions. In the United Kingdom, Article 8.4 of Directive 95/46/EC is used as a basis for ethnic data collection based on ethnic and racial categories.<sup>141</sup> There, categories are established in consultation with minorities themselves. European law does not require a more restrictive interpretation in the countries under review or across the European Union. However, while the legality of the processing of sensitive data is a given, the legitimacy of equality data collection is subject to choices and traditions.

### Categories of disability

Disability data are considered sensitive and personal in all seven countries, but this does not hamper their collection in most of them. As regards the ground of disability, no proxies are used as disability often seems to be considered as more of an “objectively” determined characteristic. Indeed, as a general rule special educational needs are established through third-party identification by medical, pedagogical and/or psychological experts assessing

<sup>140</sup> If marked by an “X,” the proxy is used in practice in public statistics (census/surveys or registers of population/pupils/workers, etc.). Any other annotation indicates that the proxy is used specifically in the context indicated by the table.

<sup>141</sup> Makkonen, *Measuring Discrimination*, 61.

readiness for school or eligibility for certain benefits or types of assistance. The data that do exist regarding children with disabilities are therefore based on the categories of disabilities which require certain forms of assistance. In most countries this assessment conducted by expert commissions generally specifies type and/or degree of disability. In most countries, data are therefore collected regarding the number of children with different types of special educational needs — the number of children in special schools and in special classes for instance. Depending on the source of such data and the methodology of their collection, this categorization may or may not provide reliable, objective and comparable data for the purposes of antidiscrimination legislation and policy.

For instance, in Bulgaria, some data on disability are collected and publicly available with regard to children with disabilities. These data are divided into different types and degrees of disability established by medical commissions. The misdiagnosis and enrollment in special schools of children of Roma origin was raised by the national expert as a significant problem, although this practice is slowly being abandoned as special schools are being closed down. Another concerning issue is the number of children with disabilities and/or learning difficulties who are not covered by any statistics as they have not gone through an assessment by an expert commission. Reportedly, such children are sometimes not enrolled in any type of formal education, or they frequently drop out prematurely due to lack of assistance or resources. In addition, different Government bodies/agencies collect data on special educational needs and disability separately, with the result that data on the number of people in need of assistance are duplicated and become unreliable.

In Romania, the Ministry of Education does not collect disability data but uses the data collected by the Ministry of Labor, although experts indicate that these data are often inaccurate. These data are provided by the medical and pedagogical assessment commissions evaluating children's special educational needs. They indicate the type and degree of disability and special educational needs, age and place of residence. The four degrees of impairment are defined by law as mild, moderate, pronounced and severe, while the nine types of disability are listed as physical, visual, auditory, somatic, mental, psychiatric, HIV or AIDS, rare diseases and/or associated disability.<sup>142</sup> In Hungary, schools are under the duty to provide data on children's disability broken down into 14 categories.

In Germany, all children go through a medical examination prior to enrollment in school, where the existence of a special educational need is assessed. Children with disabilities are defined as children receiving integration assistance in accordance with national legislation, due to physical, mental or psychological disabilities. The Berlin Special Educational Needs Regulation<sup>143</sup> differentiates between the following eight types of special needs:

- Significant visual impairment or blindness;
- Deafness, a significant hearing impairment or disturbance of auditory perception and processing;
- Significant physical disability;

<sup>142</sup> Romania/Law 448/2006 on the Protection and Promotion of the Rights of Persons with a Handicap of December 6, 2006, Article 86.

<sup>143</sup> *Sonderpädagogikverordnung*, <http://gesetze.berlin.de/default.aspx?vpath=bibdata%2fges%2fblnsopvo%2fcont%2fblnsopvo.htm&mode=all&page=1>.

- Significant speech disabilities;
- Significant and long-lasting impairment of learning and performance;
- Severe impairment of intellectual skills and related learning and development disorders;
- Significant impairment in emotional and social development as well as in the capacity to experience and in behavior;
- Significant development and communication disorder.

In France, there is no general reluctance to collect disability data. For instance, data are collected regularly on the basis of the classifications used for the application of policy measures such as the 6 percent employment quota and social security benefits.

It should be noted that categories relating in particular to disability may vary over the years and among different sources, which causes significant difficulties when it comes to comparison and analysis. For instance, in France, studies focusing on health/disability in employment deploy three main categories: (i) formal diagnosis of the disease or disability according to a more or less detailed medical categorization; (ii) use of administrative categorization (10 percent impairment; total impairment; disabled for the purposes of the quota for the employment of the disabled); and (iii) self-definition as “disabled,” or self-rating on a “health status scale” (for instance, on a 1 to 10 scale where 1 is “in very good shape”). In contrast, the opinion poll commissioned by the French equality body and the ILO on discrimination experiences uses three other criteria: “disability,” “living with a chronic illness, and “living with HIV or AIDS.”

Similarly, in several countries, including Bulgaria and Sweden, it is reported that data on disability are not always available in a disaggregated form distinguishing between the different types of disabilities identified. The Swedish Disability Movement has expressed its regret that national statistics are not disaggregated by ethnic origin and disability in its alternative report to the UN Committee on the Rights of Persons with Disabilities.<sup>144</sup>

Following the adoption of the CRPD, the Budapest Initiative in cooperation with the Washington Group for Disability Statistics has developed self-identification based disability identification questions (short and long sets of questions) compatible with the International Classification of Functioning, Disability and Health (ICF) for the purpose of gathering census and survey data.<sup>145</sup> These question sets need to be further demedicalized, and in view of the ratification of the CRPD by the European Union, to be validated at the EU and national levels with the involvement of disability organizations.

The further development of categories appears the best solution to these problems. However, national experts did not report that national stakeholders were aware of this process. Except for the notable example of the Swedish consultation involving the Swedish Disability Federation, no national level recommendations regarding disability categorizations were reported. While the Federation endorses use of the definition of disability in the Discrimination Act, no

<sup>144</sup> Annika Åkerberg, *Swedish disability movement's alternative report to the UN Committee on the Rights of Persons with Disabilities* (Swedish Disability Federation, 2011)  
[http://www.ohchr.org/Documents/HRBodies/CRPD/Future/SwedishDisabilityMovement\\_Sweden.doc](http://www.ohchr.org/Documents/HRBodies/CRPD/Future/SwedishDisabilityMovement_Sweden.doc).

<sup>145</sup> <http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf>.

agreement has been reached on categorization. NGOs in Sweden support self-identification based disability data collection, i.e., asking a direct and open question on disability without predefined alternative answers (categories).

Eurostat has not so far used the short and long disability question sets. Its 2012 disability questions inquired about the respondents' physical and mental health and whether they were hampered in their daily activities in any way by any longstanding illness, or disability, infirmity or mental health problem.<sup>146</sup>

### 3.2.2 Sources of data

Differences in the sources of available data or data on which public policies are based can also have an important impact on their reliability and usefulness. In Germany, Hungary, and Ireland these different data sources are combined and complement each other while the available data sources are very limited in the other countries under review. These sources in the relevant fields include:

- Official statistical or census data;
- Data from population or residents' registers;
- Data from surveys representing a certain portion of the population (initiated by a public or private organization);
- Data from registration processes in schools (number of children taught in special schools or taking part in minority education; registration of citizenship, migration background and/or special educational needs);
- Data based on third-party identification by teachers or head teachers, estimating ethnic origin, disability, etc.;
- Data on complaints brought to equality bodies, courts or other authorities, and on decisions and judgments adopted by them;
- Data collected and published by civil society organizations, universities, research or academic institutions or school inspectorates.

None of the selected countries has developed a data collection practice that is fully functional in terms of establishing reliable, objective and comparable data based on which effective and well informed antidiscrimination policies are developed.

A striking example of a missed opportunity to give an incentive to use available data for equality and antidiscrimination purposes is the requirement on Hungarian local governments to submit equal opportunities action plans. The sources of the data provided in these plans are often not mentioned, which indicates that some of the information may be based on assumptions or estimates rather than reliable data. In Sweden, the only data available in relation to the racial or ethnic origin ground are data on nationality and national origin based on population registers, while in Romania there hardly seems to be any data collected and made publicly available as regards the ground of racial or ethnic origin at all. It is also noteworthy that Bulgarian practice requires teachers to fill in forms regarding pupils where information on both ethnic origin and

<sup>146</sup> ESS Source Questionnaire Amendment 01, questions C7 and C8.

disabilities is included. However, the data collected on the basis of these forms are not official, nor are they available to the public. Therefore, these data cannot at present be controlled or used for public policy objectives. None of the selected countries seem to have developed a system for data collection that is fully functional in terms of establishing reliable, objective and comparable data based on which effective and well informed antidiscrimination policies are developed in the relevant fields.

In **Bulgaria**, directors of educational facilities are the source of data. Data are reportedly collected on both ethnic origin and disability on the basis of directors' and teachers' perceptions (i.e., third-party identification). However, these data are not made public and the data protection authority has not so far stepped up to verify the existence of such data and if necessary, have them published. Thus, there is no control over the legality of data collection.

In **Hungary**, there are official sources of data on disability and ethnicity in education, as well as unofficial data on the Roma. With regard to ethnicity, official sources include data on participation in minority education, data based on a child's multiply disadvantaged status (based on income and level of education combined) and on third-party identification (estimated data on Roma children collected by the Educational Authority through the National Assessment of Basic Competence). Teachers provide perceived ethnic data through the "School Questionnaire," which, however, does not contain guidance on how to determine ethnic origin. As a consequence, teachers rely on their own perceptions. It has never been tested whether the estimated data on Roma children provided by teachers are in line with the estimation of the elected local Roma leader, and there is no information available on whether such data are taken into consideration in central planning. Sociological surveys conducted by the Institute of Sociology and Economy within the Academy of Science, as well as by private research companies, rely on previous statistics (national representative Roma survey of 1993 and 2003, population census of 2001 and ethnic statistics collected before 1993 by the Ministry of Cultural Affairs) and field work undertaken in schools and Roma settlements.<sup>147</sup> These sociological surveys are unofficial sources of ethnic data in public education. They are based on third-party identification of Roma ethnic origin by school directors, field researchers and more recently on (multiply) socially disadvantaged status. NGOs and law enforcement bodies (courts, equality body and the ombudsman) collect perceived ethnic data when adjudicating discrimination complaints.

Concerning disability in public education, Hungarian Governmental Decree no. 288/2009 (XII. 15) on data obtained by the National Statistical Data Collection Program (OSAP) serves as a basis for most targeted and "mainstream" data collection. The Central Statistical Office compiles the OSAP draft program, and a related opinion is given by the National Statistical Council. At this stage national organizations of people living with disabilities can also present their views. Disability is also registered in student records.

147 See for example: Gábor Havas, István Kemény, Ilona Liskó, *Cigány gyerekek az általános iskolában*. Oktatókutató Intézet – Új Mandátum Kiadó; Gábor Havas, Ilona Liskó, *Óvodától a szakmáig* (Felsőoktatási Kutatóintézet – Új Mandátum Kiadó, 2006); Vera Messing, Emilia Molnár, *Roma és Útravaló ösztöndíjasok összehasonlító elemzése* (TÁRKI, 2007); Eszter Neumann, János Zolnay, *Esélyegyenlőség, szegregáció és oktatáspolitikai stratégiák Kaposváron, Pécsen és Mohácson* (Occasional Papers 38, EÖKIK, 2008) <http://www.eokik.hu/data/files/129435016.pdf>; János Zolnay, *Oktatáspolitikai és etnikai szegregáció Miskolc és Nyíregyháza általános iskoláiban* (Occasional Papers 16, EÖKIK, 2005), <http://www.eokik.hu/data/files/123538851.pdf>; János Zolnay, "Olvashatatlan város" *Közoktatási migráció és migrációs iskolatípusok Pécsen*. (2010) *Esély*, XXI. évf. 6. sz. For a list of publications by Gábor Kertesi and Gábor Kézdi, see: <http://econ.core.hu/file/download/kertesi/kertesipubh.pdf>.

In **Ireland**, information on the nationality background of pupils and their families was collected at primary level through a questionnaire administered by the Educational Research Centre in 2005. At secondary level, information is available on the nationality of pupils — but this field defaults to Irish nationality when no indication is given of nationality, and the reliability of information across schools is open to question. Until recently, the Department for Education and Science collected information on Traveler children only, based on the number of pupils taught by a Resource Teacher for Travelers and based on a questionnaire targeting Traveler children. In 2014, however, the Department for Education and Skills developed a Primary Online Database, which will include general information on primary level pupils, including nationality, age, gender, enrollment in mainstream or special classes, etc. This database will be populated using questionnaires filled in by parents that include non-mandatory questions on the pupils' religion and ethnicity/cultural background. The aim of the new database is to track and compare the progress of children from different ethnic and cultural groups and to ensure the development and implementation of appropriate policies and interventions.

Currently, statistics collected by this Department on special educational needs are confined to the following three areas: (i) aggregate information on the total number of pupils in ordinary primary schools taught by a Special Class teacher (classified by age, sex, type of special learning need, and other administrative data); (ii) aggregate information on the total number of pupils in Special Schools (classified by age, sex, type of special learning need, and other administrative data); and (iii) information collected at secondary level.

Separately, the Primary Administration/Payments Section of the Department collects information from National Schools on educational provision for non-English speaking pupils. The information collected refers to pupils by name, date of birth, date enrolled in school (for the first time), country of origin, class in which enrolled, English language level (code 1 refers to “Very poor comprehension of English and very limited spoken English,” and code 2 refers to “Understands some English and can speak English sufficiently well for basic communication”).

In **Romania** there is no unified coherent mechanism for data collection either on ethnicity or on disability. The Ministry of Education and the school inspectorates compile reports generated either in the context of Romanë courses or in the context of self-identification as a requirement to access benefits as positive measures for Roma pupils or students. The questionnaires on educational status used by the National Institute for Statistics that each educational institution completes every academic year do not mention disability.

In **Sweden**, the only data available on disability come from public surveys.<sup>148</sup> These are sample based surveys, such as the Survey on Living Conditions and the Labor Force Survey that also exist in other countries. Disability is identified through direct questions, hence it is based on self-identification. Data concerning special schools for children with intellectual disabilities (“*särskola*”) are provided by the Swedish National Agency for Education. These data concern children with intellectual disabilities only, because the Agency does not collect any other type of disability data.

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148 Sweden has not conducted a census since 1990, as it was considered too expensive and too “personal.”

### 3.2.3 Data collection methodologies

Depending to a large extent on the source of data and the body or authority in charge of data collection, different methods are used to gather data in the different countries. This section presents and analyzes the different methodologies followed in the selected countries. The methods of data collection fall into three groups, and are based on self-identification, third-party identification, or proxies (objective criteria).

#### *Data collection based on self-identification*

Self-identification implies that the data subject determines the characteristics that apply to him or her (such as having a certain ethnic origin or a particular disability). As far as official data from public sources is concerned, self-identification is widely used as a method of data collection through public censuses and other surveys, where the data subjects are asked to identify for instance their ethnic origin or health status, including any potential disabilities. In the Bulgarian public census, questions that may reveal sensitive data — including questions regarding ethnic origin and health status — are optional. This is also the case in Sweden as regards the questions related to disability in both the survey on living conditions and the labor force survey. However, information is not always elicited on the basis of identical questions. The direct consequence of this method is naturally that although the census may cover, for instance, a certain percentage of the population, the figures on sensitive data such as ethnic origin or disabilities will not be fully reliable as some subjects will potentially omit those questions. It is noteworthy, however, that the micro-censuses held annually in Germany, covering 1 percent of the total population, include *optional* questions on disability while there is a *legal duty* to answer questions relating to parents' nationality and duration of stay in Germany. The data from these micro-censuses seem to be used quite extensively for public policy purposes in Germany, including in the field of public education. In Ireland, it is mandatory to answer census questions, including direct questions on race and ethnic origin as well as questions that directly reveal disability. It is noteworthy in this regard that the Swedish report previously mentioned on the inclusion of questions that reveal racial or ethnic origin and disability among other sensitive personal data, examines in some detail the different possible ways of formulating such questions, and the impact of these formulations on the resulting data.<sup>149</sup>

As regards other sources of data, self-identification is used extensively, for instance by civil society organizations and equality bodies in their research work. In general, however, this method seems underdeveloped. At the same time, several interesting practices are developing in Germany where data on the “migration background” of pupils seem to be collected on the basis of self-identification as regards the language predominantly spoken in the pupil's family. Such information seems to be collected for statistical purposes in several different forms as well as during school registration. In Romania, several integration policies and positive action measures are directed at the Roma minority, such as reserved places in universities that are available on the basis of self-identification as a Roma. This measure, however, appears to be abused by non-Roma — an abuse that is reportedly not always punished by the authorities. In France, data collection that reveals racial or ethnic origin is generally considered to be suspicious even when the method is based on self-identification. This was for instance

<sup>149</sup> Al-Zubaidi, *Statistikens roll i arbetet mot diskriminering (The role of statistics in combating discrimination)*, 63 et seq.



illustrated by the debate that occurred in 2007 on the legislative proposal seeking to authorize surveys including self-identification questions on ethnic origin. Strong opinions against such data collection were voiced by the main antidiscrimination NGOs among others.

The French national expert notes that in the framework of specific studies, self-categorization of both ethnic origin and disability could be used and accepted with the approval of the CNIL, the data protection authority. However, self-identification may “hide” certain disabilities.

### *Data collection based on third-party identification*

Third-party identification implies that personal characteristics are attributed to data subjects based on an evaluation or estimation made by a third person (such as a teacher determining the number of Roma pupils or pupils with a disability in a class). This method is presented by the experts as often being the most controversial method for collecting sensitive data that reveal ethnic origin or disability, as it relies not on the perception of the data subject of his or her own personal characteristics but on the assumptions, evaluations or estimates of another person, whether a private person such as a teacher or head teacher, or of a public entity such as a public authority. At the same time, it needs to be underlined that for the purposes of tackling, proving and preventing discrimination it is sometimes useful to determine not how victims of discrimination identify themselves, but how they are perceived by others. In this sense third-party identification can, under certain circumstances and when the necessary safeguards are respected, constitute a valuable tool in countering discrimination.

Ethnic data collection based on third-party identification of some kind is reported in all seven countries covered. The most striking example of such a practice is reported in Bulgaria, where school directors reportedly collect ethnic data based on their own perceptions, unofficially and without asking for parental consent.<sup>150</sup> In Hungary, the Educational Authority collects data in the field of public education based on information provided by the school head teachers regarding the proportion of Roma pupils in each school. This information seems to be based purely on the estimates or evaluations made by each head teacher. Unofficial surveys of the Roma conducted by Hungarian academic researchers are exclusively based on third-party identification and provide anonymized, disaggregated data on which desegregation litigation heavily relies. Third-party identification based ethnic data are also sometimes collected unofficially in Germany (when registering people who do not have German as their mother tongue).

Third-party identification based disability data are officially collected in the Member States under review, except in Sweden. Independent commissions perform medical assessments of school-aged children, which form the basis for categorization. Data on numbers of children with special educational needs, who are taught in special schools or receive special education in an integrated setting, are therefore collected and processed in a way that suggests such data are considered as being based on objective criteria. This is the case in Hungary; in Germany, where data are available on the number of children receiving “integration assistance” in accordance with national law; and in Ireland. It should be mentioned, however, that data

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<sup>150</sup> Representatives of some NGOs who met during the national stakeholder meetings in Bulgaria reported such data collection practices.

collection based on the medical and other assessments made by expert commissions is subject to an important limitation in cases where it is up to the parents to request or demand that an expert commission assess their child's needs. In such circumstances, parents will often refrain from seeking this assessment from fear of stigmatization and discrimination toward their child. It is therefore a matter of great concern that the available data in Bulgaria on disabilities in public education are unreliable as they exclude a large number of children who do not have a certificate provided by the commissions.

#### *Data collection based on proxies (objective criteria)*

Personal characteristics such as ethnic origin and disability can also be surveyed indirectly, based on proxies such as country of birth or nationality, criteria that are in general considered objective, i.e., not revealing sensitive data directly. In most countries, data are collected and processed in the relevant fields using such proxies or objective criteria as nationality/citizenship, age and gender, often through the basic registration or enrollment procedures in school or in employment. As seen above, ethnic data are collected in all the selected countries based on proxies, some of which are considered objective such as nationality, while some are considered sensitive, such as non-German mother tongue in Germany. The most striking example is Sweden, where the only data available that might reveal racial or ethnic origin are based on the distinction between people of Swedish and of foreign origin, where "origin" is determined by the country of birth of the data subjects and of their parents. Such data are not considered sensitive in Sweden and are widely used in official statistics and research, although this does not appear to be a useful categorization for the development of effective antidiscrimination legislation or policy. Participation in (Roma) minority education is also considered as a proxy that denotes ethnic origin and is used to collect data in Romania and Hungary.

The general criticism leveled against proxy based data collection is that it disenfranchises minorities, fails to take their discrimination experiences into account, and is therefore liable to further stigmatize minority groups.

The use of proxies in relation to disability is not reported in the seven countries under review.

#### *Data collection based on "auto-hetero perception" and discrimination experiences*

A potentially valuable methodology for collecting equality data would be to survey data subjects' experiences of discrimination based on their "auto-hetero perception"; asking them how they believe that they are being perceived by the majority. As discrimination is typically not based on identities but rather on perceptions and assumptions it is valuable to understand how minorities believe that they are being perceived, particularly when surveying their experiences of discrimination. No such data collection was reported in the seven countries under review, but should be highly recommended and advocated for.

## 4. Pros and cons of equality data collection

The main general findings are the following:

- Disability data collection is not discussed.
- Ethnic data collection is often a taboo in public discourse.
- If there is debate, it is dominated by (i) a fundamentally flawed interpretation of the legislation and (ii) a general fear of abuse of the data.
- In the meantime, state agencies pursue questionable data collection practices that evidence gaps in national data protection schemes.

### 4.1 National debates

Historical persecution, as well as more recent forms of data abuse — genocide, forced sterilization and ethnic profiling — based on race and disability is often raised as an argument against equality data collection. These arguments conceal the real question of whether or not racial and ethnic minorities and people with disabilities have reason to fear a reoccurrence of such events and practices. Nobody asks themselves whether it is the impermissibility of equality data collection that prevents such horrendous acts from reoccurring and whether — if this is the case — the lack of equality data could in fact deter persecution.<sup>151</sup> Thus, reference to historical events effectively taboos not only equality data collection based on self-identification — particularly in relation to race and to a lesser extent disability — but also a well informed public debate. Indeed, it may be the case that those in favor of equality data collection will be labeled racists.<sup>152</sup> Strikingly, public debates do not extend to an in-depth discussion of the rights and interests balanced. In other words, neither the consequences of a potential violation of the right to personal data protection, nor of the lack of positive action measures or sanctions against discrimination, are studied on the national level.

Public debate is not reported in Romania and Germany, although an increasing number of NGOs seem to be raising the issue of equality data. Whereas Bulgarian and Irish NGOs support ethnic data collection, in France the majority of stakeholders are strongly opposed, in particular the mainstream antidiscrimination NGOs, although some minority-run antidiscrimination NGOs are in favor. Only a small number of NGOs such as the CRAN (Representative Council of Black Associations) and the CCIF (the Collective against Islamophobia in France) actively call for such data to be collected, although Eurobarometer 263 showed that the levels of acceptance of equality data collection among the French public are above average (79 percent for race/ethnic origin and 73 percent for health status). It is, however, important to note in this regard

151 Indeed, in the Hungarian context Roma leaders in favor of ethnic data collection refer to the fact that in 1944 state officials created a Roma register within three days of the date that the decision to deport Roma was taken.

152 A recent book based on a field study carried out in several disadvantaged neighborhoods in France identified the challenges faced by young people of Sahel origin in coping with tensions between their parents' culture and the autochthonous culture and their consequences for school dropout rates and juvenile delinquency. The author was violently attacked by other sociologists for having a "cultural" and essentialist point of view and for stigmatizing immigrants without examining social issues, but also praised (mostly within the political right) for breaking the "conspiracy of silence" regarding the difficulties encountered by certain immigrant populations in integrating. However, the focus of this book was not to support or oppose equality data collection. For more details, see Hughes Lagrange, *Le déni des cultures* (Paris: Seuil, 2010) <http://www.sciencespo.fr/osc/fr/content/le-deni-des-cultures>.

that the Eurobarometer 263 survey was held before the eruption of the most relevant debate in France on the topic of equality data collection. From 2006 to 2010, several relevant reports and studies were issued, including a 2006 study conducted by two researchers at the national demographic research institute (INED), aiming to identify relevant and acceptable ways to measure ethnoracial realities within French society.<sup>153</sup> This report concluded that societal reluctance mainly stems from a lack of trust in the fair use of ethnic data. Discussing ethnic origin is generally viewed as presenting a segmented view of French society, contrary to the notion of the undivided “French community/identity.” NGOs fear that statistical categorization may turn into political categorization and potentially hide “social discrimination.” The views of opponents of ethnic data collection are characterized by those of Hervé Le Bras, a respected French demographer:<sup>154</sup>

- there is no need for ethnic statistics to prove discrimination in any specific case;
- ethnic origin based categorization is irrelevant as it varies with the cultural context;
- monitoring ethnic origin within companies requires a consensus on ethnic categorization in order to make comparisons, but this represents a “hidden agenda” in support of an “ethnic quota.”

A report published in 2010 as a result of President Sarkozy’s call for consultation with scientists to produce a consensual method for measuring ethnic diversity concluded that objective data are the most useful, namely country of birth, nationality at birth or previous nationality for immigrants; *département* or territory of birth for Overseas French; and the same information for parents.<sup>155</sup>

In France, disability NGOs do not perceive data collection as a key issue. For example, the APF (*Association des Paralysés de France*) has not elaborated an agenda on this point either in general or in the field of employment specifically. Furthermore, the public data available (such as the number of companies which do not meet the 6 percent employment quota and figures on access to vocational training, unemployment rates and average levels of qualifications) seem to be quite sufficient to serve the disability agenda.<sup>156</sup>

The basic consideration in the Swedish debate is the misconception that processing sensitive data is strictly prohibited by law. It is often argued that the severe consequences of a potential misuse (for the minority communities concerned) outweigh any possible legitimate benefit of such data collection. However, ethnic and disability data collection enjoys solid legitimacy among the Swedish public (83 percent and 78 percent) as demonstrated by Eurobarometer 263, and some minority groups are calling strongly for equality data, most importantly Afro-Swedes and Swedish Muslims. The Swedish Disability Federation has endorsed use of the definition

153 Simon and Clément, *Rapport de l’enquête ‘mesure de la diversité’*.

154 Hervé Le Bras, *Statistiques ethniques : le vrai débat* (Collection Les Essais, Paris: Fondation Jean Jaurès, 2010). This essay (published by a left-wing think tank) underlines methodological differences in the use of statistical tools in order to fight discrimination and finds that ethnic statistics are irrelevant.

155 Comité pour la mesure de la diversité et l’évaluation des discriminations (COMEDD), *Inégalités et discriminations. Pour un usage critique et responsable de l’outil statistique* (COMEDD, 2010)

156 For further information about the APF’s political agenda regarding employment, see APF, *Formation et Emploi: Principales revendications de l’APF* (Association des paralysés de France, 2008) available at: <http://www.reflexe-handicap.org/media/01/00/4122653257.pdf>, 7.

of disability in the Discrimination Act. However, no agreement has been reached on the issue of categorization, while several NGOs call for self-perception based methodology, i.e., asking a direct and open question on disability without predefined alternative answers (categories).

In Hungary, the debate over ethnic data was revived by the joint recommendation of the data protection and minority rights ombudsmen published in 2009.<sup>157</sup> Events preceding the joint statement were twofold. On the one hand, fraudulent participation of majority citizens in minority elections and the State Audit Office's investigation into spending earmarked for the Roma had revealed that majority citizens abuse the self-identification based categorization of ethnic minorities by exercising minority rights — such as participation in the election of local minority representatives — and accessing positive action measures.<sup>158</sup> On the other hand, hate speech and hate crime prompted a response from the ombudsmen.

The joint recommendation focuses on the following: (i) there is a need to distinguish among the justifications and methodologies for ethnic data collection in the fields of countering discrimination, positive action measures, policing hate crimes and ensuring minority rights; (ii) the right to equal treatment outweighs the right to protection of personal data when it comes to investigating hate crimes and tackling discrimination, mainly because the potential violation of the latter is formal; (iii) given that discrimination and hate crime are based on perceived ethnic origin, ethnic data in these fields ought to be collected on the basis of third-party identification, whereas self-identification is of little relevance; (iv) the ombudsmen established objective criteria (primary and secondary) for third-party identification; (v) local minority representatives must be involved in third-party identification; and (vi) data must be collected anonymously. The minority rights ombudsman also commissioned a study on methodologies to demonstrate that anonymization of personal data is feasible in the Hungarian context.

Academics and NGO representatives made the following arguments against ethnic data collection in response to the joint recommendation:

- Ethnic data collection in education is not necessary because desegregation litigation is successful without such data.<sup>159</sup> Moreover, policy based on the multiply disadvantaged status of students is effective.<sup>160</sup>
- The proxies introduced by the ombudsmen for perceived ethnicity are based on stereotypes and may further stigmatize protected groups (skin color, place of residence, name, etc.).
- Historical experience shows that ethnic statistics can lead to human rights violations.

157 Parliamentary Commissioner for the Rights of National and Ethnic Minorities and the Parliamentary Commissioner for Data Protection and Freedom of Information, *Report on the conclusions of a study on the processing of ethnically disaggregated data*.

158 Reportedly, no criminal or civil action has been taken against majority citizens fraudulently declaring themselves as Roma.

159 This statement is factually wrong as ethnic data have been generated in court cases, or estimates generated by respondent local governments have been used. Indeed, the judgments in the *Hajdúhadház* desegregation case brought by the Chance for Children Foundation preceded the joint statement and were based on third-party identification based ethnic data collected by a court-appointed public education expert in tandem with the elected local Roma leaders.

160 It should be noted that monitoring of the impact of social class based desegregation measures on race and ethnic origin based segregation has not been conducted.

- The current political regime is not able to protect its citizens from racism, and Hungarian society is not ready for ethnic data collection.
- Perceived ethnicity violates the right to self-identification; the methodology elaborated by the ombudsmen does not answer the questions of how anonymity can be guaranteed, who can collect the data and for how long they can be kept, etc.<sup>161</sup>

Supporters of ethnic data collection include equality bodies, ombudsmen, statisticians, demographers and academics dealing with minority rights and discrimination and — in most countries — (antiracist) NGOs. In Sweden, the ILO and ECRI took action in favor of data collection through conducting research and organizing a roundtable discussion. The ILO has been active in France as well.

In general, opponents come from the ranks of data protection agencies, statisticians, the political establishment and public officials, as well as from a smaller group of NGOs — except for in France, where mainstream antiracist NGOs also oppose ethnic data collection but the INED, the national demographic research institute, has shown itself to be more receptive. In Sweden, Jewish representatives are against ethnic data collection, and Roma representatives generally seem to be more opposed than supportive.

Views on disability data collection need to be canvassed in detail. High ranking political stakeholders have engaged in the debate in France and Sweden, with no success in the former and relative success in the latter.

## 4.2 Summary of debates at national stakeholder meetings

Disability stakeholders have not indicated wariness in relation to data collection, but the degree of openness varies among ethnic minorities. At the national stakeholder meetings of the EDI project Muslim and Black communities demanded data, Roma communities in Sweden and Hungary expressed “data fatigue” (the view that there are too many data and reports but not enough concrete action being taken), while Jewish communities did not seem to be open to data collection. In general, NGOs are far more receptive to equality data collection than public authorities, with the exception of France, where only a few NGOs support data collection and the debate is in fact being led by statisticians. Notably, however, even in France, where in 2006 the INED conducted statistical experiments to determine the willingness of the *general population* to provide information on their ethnic origin based on racial self-categorization, 66 percent of the respondents would permit the collection of ethnic data in employment (public or private); 90 percent in scientific studies; and more than 85 percent in population censuses.

Experts recommend self-identification of disability, whereas national disability NGOs call for further demedicalization of disability categories. However, in the field of education they support the approach that seeks to identify special educational needs in order to accommodate children’s needs. The most burning issue is the purpose for which disability data are collected. NGOs call for data that measure gaps in achievement. No legislative amendments are needed for data collection on disability.

<sup>161</sup> For more details, see (in Hungarian): <http://www.ideaintezet.hu/en/node/85>.

As an exception, in Hungary ethnic data has been collected on the basis of third-party identification with the involvement of elected, local Roma minority leaders in order to defend legal claims — in particular those relating to discrimination. However, even though tailor made, this ethnic data collection methodology did not seem replicable elsewhere, with the possible exception of Bulgaria.

Stakeholders did not recommend amendments to existing legislation, with the exception of the Bulgarian expert. Interestingly, she recommends legislative amendment in order to ensure that data in the field of education is collected on the basis of self-identification and with the consent of the persons concerned, i.e., in compliance with European law.

The hypothesis that national data protection agencies would automatically block data collection — particularly on ethnic origin — was not supported by stakeholders, although the Romanian stakeholders identified a strong need to win the data protection agency's support. The main issue was that data protection laws are not used to their full potential in relation to equality data collection. There is a need to shift the focus from the prohibitionist approach to the exemptions. This would require a further push — preferably from the European level — in a form more stringent than good practices, guidance or practice notes. National experts indicate a strong need for handbooks targeting various stakeholders. Indeed, as the French national expert underlines, the most important disincentive to collecting equality data in public employment is the “fear of stakeholders to do it wrong.”

While the abuse of data was not a concern raised in the context of disability, national stakeholders were wary of repeated instances of ethnic profiling and called for safeguards to ensure such practices do not occur in the future.

Stakeholders also called for systemic planning to ensure equal opportunities and prevent discrimination in public education. In Ireland and Sweden, planning based on existing categories included in the national antidiscrimination legislation appears adequate (although insufficiently implemented and monitored), while in Germany some of the proxies appear inadequate to plan for equality based on ethnic origin. The ideal way forward towards effective equal opportunities planning would be to measure ethnic and disability equality on the basis of ethnic and disability categories. Failing that, the essence of the need addressed by positive action measures should be more precisely identified. In Germany the general sentiment is that the use of language proxies should be discontinued and the child's language skills should be taken into account.

## 5. Conclusions and recommendations

This section takes stock of recommendations to shape future developments and provides a model for future action.

### 5.1 Message in a nutshell

Stakeholders call for data collection that respects the following “binding core principles,” a term advanced at the German national stakeholder meeting: self-identification, voluntary and anonymized data collection that is based on knowledge of the purpose of data collection, community consultation throughout the process and the possibility to choose multiple or intersecting identities.

Recommendations focus on the importance of (i) developing precise categories; (ii) uniformity of categories across administrative units; (iii) amending or changing categories if necessary — including the demedicalization of disability categories; (iv) ensuring that children are registered in the relevant categories; and (v) building trust through the involvement of equality bodies and ombudsmen institutions. As indicated by experts and stakeholders participating at the roundtable discussions, in all the seven Member States reviewed, political will to collect equality data is lacking. The overwhelming majority of national stakeholders supporting equality data collection look to the EU level for leverage, which is stands to reason in a multilevel governance structure where the debate at national level has stalled. At the national level, many recommend that the data protection authorities collaborate with equality bodies in resolving data collection issues.

### 5.2 The equality data model for action

At the EU level, various stakeholders have taken steps to promote equality data collection, but more is to be done going forward. Some work has already been undertaken, such as the identification of allies, of the pitfalls in the present national frameworks and of good practices that can be adapted to the European context. The FRA has opened consultations with Member States on the implementation of National Roma Integration Strategies, while in the framework of the European Social Survey, more particularly in the field of employment, new ethnic categories have been piloted by Anthony Heath and his colleagues. However, Eurostat does not seem to engage in ethnic data collection either in relation to the National Roma Integration Strategies or the European Structural Funds, and its work on disability data reportedly remains within the boundaries of the framework set by the Washington Group and the Budapest Initiative. On the other hand, the relative openness felt at the national level on the part of the data protection authorities has not been tested at the European level, namely vis-à-vis the Article 29 Working Group.

Regrettably, a single actor that has the competence as well as the willingness to drive and coordinate the process has not yet stepped forward and it now appears that tangible results can only be achieved through cooperation among the relevant European institutions. Moreover, except in the isolated initiative taken by the Swedish Equality Ombudsman (now aborted), the binding principle of community consultation has not so far been respected. This seems to have created a legitimacy deficit at all levels. The way to overcome this legitimacy deficit is



obviously through opening consultations with community representatives at the European as well as the national levels. At the EU level, the FRA and the European Commission may be best suited to sit at the wheel, whereas in the national context, equality bodies and ombudsmen can drive this process as reportedly NGOs perceive them to be by far the most trusted institutions. In order to facilitate further action, it appears indispensable to draw up question sets and categories under the guidance of the FRA with the involvement of NGOs, and pilot them through Eurostat surveys.

***The process can be modeled as follows:***

1. Given that political will to collect equality data at the national level is lacking, engage in parallel top-down and bottom-up approaches starting at the EU and local levels.
2. Map allies at both levels, such as Eurostat, the Fundamental Rights Agency, the European Data Protection Supervisor, Equinet and other European umbrella organizations on the one hand and local communities, NGOs, national equality bodies, ombudsman, national statistical offices and data protection authorities on the other.
3. Demonstrate the pitfalls of present data collection practices.
4. List the “binding core principles” of data collection:
  - self-identification;
  - voluntary response, i.e., every individual has the right to opt out of data collection;
  - anonymous data collection;
  - informed consent — purpose of data collection;
  - community consultation throughout the process, commencing with the naming of categories and identification of disability and ethnic origin question sets through agreeing on potential data collection purposes and ending with the involvement of community representatives in the analysis and dissemination of the data;
  - the right to choose multiple and intersecting identities.
5. Collect and compare data collection methodologies and develop a draft methodology.
6. Consult local and European stakeholders.
7. Draw up a research, community empowerment, advocacy, and litigation strategy.
8. Bring together local and European stakeholders. Be aware that the opt-out model means there is no need for consensus among all communities.
9. Foster exchange among the stakeholders.
10. Implement strategy in a way that ensures consistency between the European and national levels and in order to have as a minimum *comparable*...
  - European and national categories of disability and ethnic origin;
  - European and national question sets on disability and ethnic origin;
  - European and national question sets on disability and ethnic origin based discrimination experiences;
  - European and national level equality data;
  - European and national level equality policies and positive action measures.

If the model is embraced by stakeholders, the following steps need to be taken. The FRA and Eurostat need to develop or amend the categories and question sets as well as to agree on potential research objectives in consultation with disability and ethnic minority representatives. Then, they need to pilot and update their research methodologies. National statistical offices should be engaged with a view to facilitating them to take on board the new tools and adapt their research methods. Provided the “binding core principles” of data collection are respected, there is no legal ground for the European Data Protection Supervisor and/or national data protection authorities not to endorse or authorize research. However, political support is needed at the EU level in order to embed the new methodological tools at the national level. Such support may come from the European Commission and Parliament. EU stakeholders have the capacity and the competence to relaunch the debate on equality data collection and go beyond the soft measures of sharing best practices and publishing guidance and tools to ensure that changes on the ground actually take place.

### 5.3 Recommendations for action at the European level

- The European Commission, the Fundamental Rights Agency, Eurostat and the European Data Protection Supervisor should adopt and abide by the “binding core principles” of equality data collection as well as categories and question sets pertaining but not limited to disability and ethnic origin. The binding core principles should include the following: self-identification, voluntary response (i.e., every individual has the right to opt out of data collection), anonymous data collection, informed consent as to the purpose of the data collection, and community consultation throughout the process, commencing with the naming of categories and identification of disability and ethnic origin question sets and ending with the involvement of community representatives in the analysis and dissemination of the data.
- Given their binding nature, the core principles should be enshrined in a legal instrument taking the form of a Commission recommendation on the collection of equality data with a view to defending legal claims and designing positive action measures under EU antidiscrimination law, a directive, or specific provisions in the draft Data Protection Regulation. The material and personal scope needs to correspond to European antidiscrimination law. A reporting obligation should be imposed on Member States in relation to both objectives. The legal basis of such a recommendation is provided by Article 19 of the Treaty on the Functioning of the European Union (TFEU), Article 8.4 of the Data Protection Directive, the antidiscrimination directives — particularly Articles 5 and 15 of the Racial Equality Directive — and Article 31 CRPD.

- The Commission needs to define the goals of equality data collection to be carried out by the FRA and Eurostat, including outcomes relevant for implementing, monitoring and fulfilling the goals of:
  - the antidiscrimination directives, including data on registered discrimination complaints, decisions and judgments per ground and per field;
  - the Europe 2020 Strategy;
  - the European Framework Strategy on Effective Roma Integration;
  - the European Social, Structural and Investment Funds;
  - the CRPD (and, particularly, its Article 31).
- The Commission needs to encourage the FRA and Eurostat to establish consultative mechanisms and consult disability and ethnic minority communities in order to develop and test categories. Particularly, Eurostat needs to demedicalize question sets used to collect disability data, and should be urged to resume its project on ethnic data collection.
- The FRA should poll European citizens again as to their readiness to provide sensitive personal data in order to fight discrimination and implement positive action measures.

## 5.4 Recommendations for action at the national level

### 5.4.1 Common recommendations for the countries under review

- Censuses, household surveys and administrative registers need to collect data on disability and ethnic origin-based discrimination experiences. This data could be collected based on “auto-hetero perception.”
- Data collection needs to be included as a central element of coherent and effective public policies for equality and nondiscrimination.
- Awareness needs to be raised among disability NGOs about the short and long question sets developed in the wake of the adoption of the CRPD. National statistical offices need to be encouraged to adopt these question sets for research purposes as well as to undertake monitoring of Article 31 CRPD on the basis of these question sets.
- Proxies used to substitute the category of ethnic origin — particularly those excluding instead of including ethnic minorities (e.g. “foreign background” in Sweden, etc.) — need to be challenged through advocacy, their use suspended and categories of ethnic origin introduced into data collection.
- Alternatively, such proxies may be challenged through legal action in two or three distinct ways: (1) by relying on data protection laws on the collection of sensitive data — namely the obligation to obtain the data subject’s consent — in countries where proxies are collected on the basis of third party identification, including Germany, France and Sweden; (2) by relying on antidiscrimination law to claim that in comparison to the category used to denote ethnic majority people, the ethnic

minority proxy is directly discriminatory, because it is not designed to signify who those people are but who they are not (non-German speaking, not born in France or parent not born in France, non-Swede — even if born in Sweden), that the proxy fails to serve the purpose it is intended for or that it does not have a legitimate purpose — what purpose does it serve to categorize a Swedish Muslim born in Sweden as non-Swede?; (3) by relying on antidiscrimination law to claim that the use of the proxy constitutes harassment as it creates a hostile and degrading environment within and beyond the realm of statistical surveys as these proxies are in fact used to denote ethnic minority groups and as such enforce a discourse of exclusion and/or portray group members as somehow lacking — for instance in relation to language proficiency. Courts would be asked to order defendant schools, school inspectorates, statistical offices, etc. to discontinue the violation.

- Challenges against existing ethnic and disability categories and question sets may be advanced in the framework of advocacy action, or failing that, litigation. The basis of the claim would be direct discrimination, alleging that in comparison to the category of non-disabled and/or of majority ethnic origin, the questionnaire fails to properly define the given category, i.e., the category of disability and/or ethnic origin. The disability question sets adopted by the Washington Group and the three-tier definition of ethnic origin proposed by MPG could serve as benchmarks for such claims. Courts would be asked to order defendant statistical offices to discontinue the violation and remedy the breach by including the questions put forward by plaintiffs. In order to prove a prima facie case and/or promote questions sets agreed within the communities, the results of NGO consultations could be channelled into the process through expert opinions or witness statements.
- From a procedural perspective, such claims would be relatively easy to bring. Abusive data handling practices may be challenged by one person or organization, who alone can put an end to the said practices either before national data protection authorities or courts. Challenges under national antidiscrimination laws could go before the equality bodies, which have quasi-judicial powers in all the countries except for Germany.<sup>162</sup> Alternatively, with a view to enhancing the advocacy potential and generating media attention, they could go before civil courts. In Bulgaria, Hungary and Romania, challenges could be mounted as representative actions (*actio popularis*) and in Sweden the equality body may be persuaded to bring a case to court alongside NGOs that have legal standing to litigate such matters. Should a preliminary referral to the Court of Justice of the European Union (CJEU) become necessary, the cases could shed light on the implementation not only of the antidiscrimination directives but of the Data Protection Directive as well. In countries where only individuals have standing, cases may proceed to the European Court of Human Rights, should they not be referred to the CJEU. However, the standing of disability and minority rights NGOs should be explored, as they may have standing in Strasbourg once they establish that they act on behalf of their members.

162 See Isabelle Chopin and Catharina Germaine-Sahl, *Developing Anti-Discrimination Law in Europe: the 28 EU Member States, the Former Yugoslav Republic of Macedonia, Iceland, Liechtenstein, Norway and Turkey compared*, Thematic report of the European Network of Legal Experts in the Non-discrimination Field (Luxembourg: Office of the Official Publications of the EC, October 2013), 156-162.

- Advocacy and/or litigation may also focus on freedom of information requests for access to equality plans, data on the implementation of equality plans or simply data as indicated in the country-specific recommendations. Once data are provided, further action may be taken, depending on the trends emerging from the data. Should data not be provided based on the argument that it cannot be collected, responses could be challenged relying on, among others, Article 8 of the Data Protection Directive providing exceptions to the prohibition of collecting sensitive data, Article 31 CRPD, or the relevant provisions of the antidiscrimination directives relating to positive action measures and effective remedies and sanctions.
- From a procedural perspective, pursuing freedom of information requests appears to be the easiest and most straightforward route to take. However, the actual question needs to be very cautiously crafted both from a legal as well as an advocacy perspective.
- If challenges remain within the ambit of public education, the national courts, the CJEU and the ECtHR will have competence to act. This may be a bit trickier in relation to disability, where Member States and the European Union itself are bound by Article 31 CRPD, but the Employment Equality Directive only extends to university and vocational education.
- Should the scope of legal challenges regarding access to data fall outside the field of education — and relate to census questions for instance — further analysis is needed on their viability under Article 8 (and Protocol 12 if ratified by the Member State in question) of the European Convention on Human Rights. Their referral before the CJEU and the applicability of the European Charter of Fundamental Rights depend on the material scope of the Racial and Employment Equality Directives.

#### 5.4.2 Country-specific recommendations

##### Bulgaria

- The Council of Ministers National Council for Cooperation on Ethnic and Integration Issues should act as the national focal point for NGO consultation on ethnic data collection.
- Cooperation between institutions needs to be strengthened, particularly between the Commission on Data Protection and the Commission against Discrimination with a view to producing guidelines and a handbook on equality data collection.
- Advocacy is needed to call for the National Statistics Institute to collaborate with the Ministry of Education to ensure the full comparability of education databases.
- The National Statistics Institute needs to extend coverage to all minority households — whether registered or not.
- Data on children with disabilities collected and made public by the Ministry of Health (medical commissions) need to be complemented and compared with the data collected by the Ministry of Education (pedagogical commissions) to ensure greater reliability.

- The Ministry of Education should commission a national survey on children with disabilities. The survey should include screening for learning difficulties by speech and language teachers.
- The national database for people with disabilities established by the Agency of People with Disabilities and based on data from different ministries needs to receive continued support and resources. The agency needs to involve NGOs and allow them access to data.
- The Commission on Data Protection should publish its general guidelines and case by case decisions pertaining to data collection on Roma and/or persons with disabilities.
- In censuses and surveys, ethnic origin question sets need to be reviewed in order to capture characteristics beyond minority language use or religion, particularly in relation to the Roma.
- The annual school enrollment forms should serve as the basis for ethnic and disability data collection by school directors, based on voluntary and informed consent, as well as interviews with students and their parents. The Ministry of Education and school inspectorates should be responsible for such data collection at the national level, ensuring anonymity.

## Germany

- Data pertaining to the harassment of students with disabilities and of minority ethnic origin should be collected at school, *Länder* and the national level.
- It is necessary to collect equality data in relation to the following indicators: educational outcomes; representation of groups across education; differences in educational outcomes amongst students of different ethnic origin; and how these outcomes are the product of structural discrimination.
- The German equality body, the FADA, should provide the necessary interdisciplinary focus for future research on discrimination experiences, or competence needs to be delegated to another state agency, such as the Statistical Office.
- The “non-native German speaker” proxy (NDH) is not suitable for indicating special needs for additional tuition or ethnic minority background, therefore its use needs to be suspended. Minority groups thus labeled need to be consulted on the purpose and use of this proxy order to create a tailor made category, e.g. based on the level of proficiency in German.

## Hungary

- Given that in Hungary three different data collection methodologies are in use, there is a need to differentiate the methodologies and proxies according to the goal (establishing discrimination, planning public policies, etc.) and conduct research into the impact of the different types of methodologies used in Hungary.

- The use of proxies that do not allow discrimination to be measured should be suspended or supplemented with questions on discrimination experiences.
- National level bodies need to be established to bring together on the one hand NGOs representing the Roma and on the other hand those representing people with disabilities to consult on data collection methodologies and surveys.
- The implementation of legislation on the collection of ethnic data in special education adopted following joint advocacy by the European Roma Rights Centre and the Chance for Children Foundation as a result of a settlement of a lawsuit needs to be monitored in collaboration with Roma stakeholders.
- The system of equal opportunities action plans in public education (promoting the integration of multiply disadvantaged children and tackling discrimination) which were a mandatory precondition for participation in any national or international tenders allocating resources for education should be formally reinstated.
- Under-registration of children as multiply disadvantaged needs to be addressed through awareness raising and penalties for schools and local authorities.
- Given that the “multiple disadvantage” proxy has failed to measure racial discrimination or segregation in education, the recommendation of cross-checking ethnic data obtained on the basis of parental self-identification with third-party identification data should be considered.
- The implementation of equal opportunity plans should be monitored in collaboration with NGO representatives of the target communities.

## **Ireland**

- Ireland should ratify the CRPD and ensure that children with special needs moved to mainstream schools are tracked through dynamic data showing their situation, development and achievements.
- Special educational needs should be the focus of disability data collection in public education, rather than specific subcategories of disability. This should be taken into account in the current development of a Special Education Administration System.
- Potential victims of discrimination and vulnerable groups need to be properly informed about the merger of the Equality Tribunal with labor law institutions. The scope and work of the new merged institution needs to be monitored, in particular as regards discrimination cases beyond the employment field.
- Awareness raising activities should target the Roma community to support the Roma population in self-identifying as “Roma” in the 2016 census (under the category “other”) to build a case for a specific category of “Roma” in future censuses.

- The Department of Education and the Department of Justice need to hold consultations with minority stakeholders on ways to enhance the reliability of data based on voluntary self-identification.
- Easy to read commentary needs to be prepared for the new circular accompanying the questionnaires on migration and ethnicity in primary school registration, both to be released from September 2014 by the Department of Education.
- The Central Statistics Office's special modules in household surveys on discrimination need to produce disaggregated data under "ethnicity" and include Travelers. In addition, the Central Statistics Office should examine the possibility of developing a special module on Travelers.

## Romania

- The 2007 Ministry of Education order on desegregation needs to be implemented. The Ministry of Education should also have a section on segregation in its annual report.
- The National Agency for the Protection of Private Data should produce guidelines on how to collect equality data in cooperation with the equality body (the National Council for Combating Discrimination) in order to measure discrimination and the implementation of desegregation measures.
- The National Agency for the Protection of Private Data should implement its 2009 decision to impose a prior check of any sensitive data processing, to ensure that the safeguards are respected. It should issue guidelines in relation to legal provisions making equality data collection mandatory — such as in the case of the above segregation order.
- (During the amendment of the Antidiscrimination Ordinance and Law 448/2006), equal opportunities planning should be introduced as a precondition for accessing EU funds. This would ensure compliance of Romanian antidiscrimination law with EU law requiring effective, proportionate and dissuasive sanctions.
- Advocacy needs to be directed at the Prime Minister's Office and trickle down to the National Data Protection Authority, the Ministry of Labor, the Ministry of Education, the equality body, the National Agency for Roma, the National Institute for Statistics and university faculties of sociology to develop adequate instruments such as:
  - 1) Secondary legislation (orders and decisions) providing for the obligation to collect equality data and for clear procedures including all necessary safeguards;
  - 2) Guidelines/handbooks explaining the secondary legislation and procedures;
  - 3) Training curricula for the data protection officers present in each data controller, with training to be piloted before its institutionalization by the National Data Protection Authority and the equality body for each type of controller (collaboration agreements would be needed).



## Sweden

- In Sweden, disability categorizations designed quickly after the adoption of the CRPD should be discussed with the groups concerned. The WHO classification (International Classification of Functioning, Disability and Health) — which is health-based — should be substituted with ones that comply with the CRPD and are the product of consultation.
- Categories used by the crime prevention agency to record hate crime (e.g. Afro-Swedes, Roma) should be adopted and used by other institutions.
- The Equality Ombudsman (DO) should publish the data on complaints disaggregated per ground, group, and field to support NGO advocacy. It should also be possible for complainants to tick several boxes to report multiple forms of discrimination.
- The participatory decision-making model used for gender equality should be extended to other equality grounds. Advocacy should demand provision of data, representation and power, and the mainstreaming of equality.
- Public inquiries taking place into the situation of the Roma should be extended to other minority groups, including the Muslim community and Afro-Swedes.
- The “foreign background” category needs to be suspended as it is stigmatizing and ethnic minority communities need to be consulted on the new category.
- Categories of country of birth and categories based on geographical continents (Europe, Asia etc.) need to be reviewed. The legitimacy of categories of “ethnic Swede” and “other ethnic origin” with the option to voluntarily declare one’s ethnic origin (other than Swedish) needs to be tested, bearing in mind that Swedish Finns and the Sámi wish to retain the explicit categories of “Sámi” and “Swedish Finn.” Categories used in the national antidiscrimination legislation need to be retained, with the proviso that country groupings based on sociocultural criteria are used instead of ethnic origin.
- Schools’ equality plans need to be monitored and effectively implemented. School principals should be under a duty to evidence the measures taken to implement the equality plan, and this duty should be enforced with sanctions.
- A general survey on inclusion/exclusion experience of pupils covering several grounds of discrimination should be conducted, possibly based on the existing “security surveys” and/or the attitude surveys organized by the National Education Agency. To increase political pressure, different interest groups should join in such a project.

## France

- The possibility of expanding the notion of “public interest” within the data protection legislation should be explored, so as to possibly reduce the procedural requirements on the collection of equality data (particularly, but not only, as regards research by the equality body). For this purpose advocacy should target the CNIL.

- Advocacy needs to target the administrative bodies responsible for implementing public policies on equality and non-discrimination in different fields, including public employment.
- With regard to disability more nuanced and detailed data should be collected than the data gathered through the implementation of the 6 percent employment quota, possibly on the basis of self-identification.
- A formal duty should be imposed on public employers to provide equality planning (based on the practice of “diversity charters”).
- The effective implementation of the disability quota in employment needs to be further monitored and data need to be collected for this purpose, not only on recruitment and employment levels but also on promotion.
- Use existing inquiries and reports, including from the EU Fundamental Rights Agency, to push for more detailed research.
- Awareness needs to be raised among minority groups of the usefulness of equality data and of creating inclusive categories. Minorities need to be supported at the local level to develop positive identities and debunk myths about the values of the French Republic conflicting with minority identities.
- The usefulness of existing statistical categories (nationality of data subjects and their parents and country of birth) for the purposes of ensuring equality and combating discrimination needs to be challenged, in particular regarding “invisible” minorities such as French Roma and citizens from French overseas *départements* and territories.
- Mapping should be undertaken of NGOs open to the possibility of equality data collection, to evaluate the feasibility of introducing and integrating the data issue into other projects and activities.

## 5.5 Good practice examples

Commendable good practice examples on national level include the following:

- Under the 2007 Ministry of Education order on desegregation, Romanian schools should send an annual report to county inspectorates detailing the ethnic makeup of classes, based on parents’ identification of their child.
- In July 2014 the Hungarian Public Education Act was amended to permit the collection of ethnic data in relation to special educational needs children. Collection will be based on parental self-identification of the child undergoing diagnosis. The Chance for Children Foundation has consulted Roma mothers on the Roma minority question set, but it remains to be seen whether the Ministry will take into account the results of the consultation in designing its questionnaire.

- The Hungarian ombudsmen issued joint recommendations on ethnic data collection.
- Cooperation between the French equality body and the national data protection authority (CNIL) has resulted in the production of guidelines aimed at public employers. In particular, this document highlights strict boundaries in sensitive data collection such as on race and health/disability.<sup>163</sup>
- Consultations have taken place in Sweden growing out of a study commissioned by the Government canvassing target group opinions on equality data collection.
- In Sweden, data on hate crime is disaggregated by categories (e.g. Afro-Swedes, Roma). Annual reports from the crime prevention agency provide model categories.
- The Swedish gender equality model is instructive for both disability and ethnic minority advocates: their campaigning should focus on provision of data, representation, power and the mainstreaming of the equality ground.
- German research using situation testing is planned by the equality body for 2013.
- In 2011, the Bulgarian Commission on Personal Data Protection instructed the National Statistical Institute that ethnic identification in the census cannot be mandatory. During the 2011 census, Roma and Turkish data enumerators and language assistants were employed. Every individual household was counted, on the basis of its actual — not legal — addresses.
- Ireland has adopted policy initiatives such as the Strategy for Statistics of the National Statistics Board and the “Towards 2016” agreement adopted through cooperation between different social stakeholders such as the government, employers’ organizations and trade unions, the community and the voluntary sector.
- The Irish Central Statistics Office introduced a unique ethnic identifier question in the census in 2006, replacing a Traveler question. In addition, an ethnic identifier was introduced by the Department for Education and Skills for primary education in 2014.
- The Irish Central Statistics Office also funded the NGO Pavee Point to produce a DVD to encourage Travelers to fill in the census. Regional supervisors of enumerators received training on Travelers and if they faced problems, they could contact Pavee Point for support in finding a solution with local groups. This helped increase the response rate among Travelers.

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163 Défenseur des droits et Commission Nationale de l’Informatique et des Libertés (CNIL), *Mesurer pour progresser vers l’égalité des chances*.

## 5.6 Concluding remarks

This report publishes findings about seven Member States that represent the diversity of approaches and practices of equality data collection in the European Union. While the national level seems to be locked in self-inflicted taboos surrounding disability and ethnic data collection, European institutions, such as the Fundamental Rights Agency and the European Social Survey, collect data in a way that respects European law, i.e., within the scope of the exceptions prescribed by Article 8 of the Data Protection Directive and generally on the basis of open questions about disability and ethnic origin.

However, there is room for further development at the EU level, primarily through the development of demedicalized disability and composite ethnic origin categories that also capture discrimination experiences in surveys. Moreover, the Commission is faced with a great need for guidance, manuals, handbooks, capacity building and training of key stakeholders, including data protection authorities, equality bodies, departments of education and school/labor inspectorates. Some soft measures, such as guidance, handbooks and the sharing of good practices, have already been introduced to guide those who want to “do it right” and ensure that they can actually collect equality data without running into difficulties at the national level.

The European Commission is uniquely placed to leverage national debates and curtail the various unlawful practices presently in use at Member State level. This report concludes that it needs to take a bolder step with regard to the collection of equality data. In the present European context the adoption of the “binding core principles” of equality data collection is a precondition of progress. They can be adopted in various forms ranging from a Commission recommendation to a directive or additional provisions in the draft Data Protection Regulation. Another issue that needs to be taken up at the EU level is the definition of the purposes of data collection. They may be limited to measuring outcomes under the antidiscrimination directives and the CRPD, but they may also encompass outcomes arising from EU-funded projects and social policy measures.

The development of disability and ethnic origin categories requires first consultation with all the communities, but eminently with those wishing to be measured — such as Muslim and Black communities. Disability categories need to be demedicalized and special educational needs categories should be more widely used in education. A complex approach to the categories and question sets of ethnic origin is desirable. This would capture identities tied to ethnicity (minority culture, language, religion and cultural traditions), geographical origin and discrimination experienced on the basis of real or assumed minority ethnic origin, including based on “auto-hetero perception.” The new categories need to be tested at the European level with a view to measuring gaps in achievement.

Advocacy and legal challenges are needed to steer national debates away from taboos; question unlawful, harmful or simply unsuitable data collection practices; and call for the inclusion of disability and ethnic minority communities in the process. Third party identification and proxies that stigmatize are criticized by communities across the seven Member States studied. Instead, data collection on the basis of the “binding core principles” is called for. It is now time to take the next logical step toward making equality a reality in Europe; a step which cannot be taken without reliable equality data.





The Open Society Foundations work to build vibrant and tolerant democracies whose governments are accountable to their citizens. Working with local communities in more than 100 countries, the Open Society Foundations support justice and human rights, freedom of expression, and access to public health and education.

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The Equality Data Initiative (EDI) aims to develop research on, and increase awareness of, the need for data regarding specific minority groups in the European Union.

Reliable data is needed to ensure equality and actively fight discrimination. Data does this by measuring inequalities and allowing the development of positive solutions to inequality such as targeted social policies. Data also allows us to monitor whether these measures work.

The Equality Data Initiative (EDI), initiated by the Open Society Foundations, is implemented in collaboration with the Migration Policy Group and the European Network Against Racism. Its goal is to enhance the measurability of (in)equality for groups at risk of discrimination. The EDI has six components including consultation with established experts, comparative policy-oriented research resulting in a comparative report, identification of, and consultation with, national stakeholders, national and EU targeted advocacy, and strategic litigation.