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SPECIAL ISSUE • The many faces of disability in evidence for policy and practice

research

How useful are equality indicators? The expressive function of 'stat imperfecta' in disability rights advocacy

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Background: The measurement of equality is often difficult for groups who are weakly defined or poorly represented in official datasets. Social statistics are an essential component in rights recognition and advocacy because they make protected groups of persons visible and reveal the extent of their inequalities in comparison with population norms.

Aims and objectives: This paper examines how disabled persons have been included, or not, in EU statistics used for evidenced-based policy – for example in the European Semester process concerning Member States' employment and social policies, or in monitoring compliance with international human rights standards under the UN CRPD.

Methods: Over a period of a decade we mapped and disaggregated disability data from the main European social surveys, examining the availability and limitations of different sources to answer various policy questions.

Findings: The analysis produced indicators revealing stark inequalities between disabled and non-disabled persons but raised challenging questions about data quality, reliability and comparability. This revealed tensions in engaging the trust of policymakers in less familiar, or less reliable, data concerning minority groups.

Discussion and conclusions: Despite limitations of precision, imperfect statistics often retain a strong expressive function in human rights promotion. Greater investment is needed from governments and statistical authorities to strengthen disability equality data and indicators concerning marginalised rights holders.

Key words Disability equality • statistics • outcome indicators • rights advocacy

Key messages

- Disability equality has not been mainstreamed very effectively in EU public statistics.
- A wide variety of public data indicate unequal outcomes for disabled people across the EU.

- Statistical weaknesses arise from data definition and from inconsistencies in data collection.
- Despite limitations, imperfect statistics achieved a strong expressive function in rights advocacy.

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This paper is about the challenges of using public data and statistics to advocate for minority groups in policy processes. Public investments in equality indicators make social inequalities visible and more governable but the quality of public statistics concerning minority groups (such as ethnic minorities, children or disabled people) is often weak. This presents a challenge for evidence-based advocates of minority rights –the smaller the minority, the greater the challenge. The risk of statistical invisibility is compounded when (legally and morally) strong policy claims are undermined by resistance from policymakers to (statistically) weak or unfamiliar evidence. We argue that the commitment of public authorities to invest in equality data, and to publish it, has an expressive policy function as well as a technical measurement function.

Population sample surveys form a large part of the evidence base on social policy outcomes in the EU, yet these have not always targeted or controlled for the statistical representation of minority population groups. Consequently, the inequalities experienced by such groups are not always visible or easily disaggregated from the datasets most commonly used in high-level policy coordination, such as in the European Semester process concerning Member States' employment and social policies, or in monitoring compliance with international human rights standards. The paper explores these issues using examples from a decade-long research effort to mainstream disability equality indicators in EU policymaking and monitoring.

Background

The policy context for disability equality in Europe is one of multilevel governance. The social policies that have the greatest impact on disabled people's everyday lives lie mostly within the competence of national or local governments but these policies, and investment priorities, are also monitored and coordinated at the EU level (including the collaborative production of social statistics). Layered on top of this, disability rights are monitored globally within the framework of the United Nations human rights system. Aligning an evidence base to support these multilevel governance processes presents a challenge.

The context for evidence-based policy

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is a comprehensive human rights treaty, formalised in 2006 and subsequently ratified by the EU and all its Member States. It covers all areas of life and is underpinned by the goal of 'full and effective participation in society on an equal basis with others'. Article 31(1) obliges each party to 'collect appropriate information' and the guidance

envisages reporting of 'Statistical data on the realization of each Convention right' ([Committee on the Rights of Persons with Disabilities, 2009](#)). This means that the EU, as a party to the CRPD, is expected to measure and report on the equality of disabled persons' participation in all relevant policy areas.

The EU concluded the CRPD in 2010, the same year it launched a ten-year strategy 'for jobs and smart, sustainable and inclusive growth' (known as EU2020) and a ten-year European Disability Strategy 2010–2020. The latter also included a commitment to develop disability statistics, data collection and monitoring, notably in areas such as employment and social inclusion relevant to EU2020. At the end of this strategy period it is relevant to ask how this progressed and how it might be improved. We focus mainly on the use of statistical indicators as evidence of disability equality in the 'European Semester', which is the main annual policy coordination cycle supporting EU strategy ([Verdun and Zeitlin, 2018](#)).

The definition and measurement of disability is contested ([Altman, 2001; 2014](#)), but Article 1 CRPD assumes that 'disability' arises in encounters between 'people with long-term physical, mental, intellectual or sensory impairments' and the barriers that 'hinder their full and effective participation in society on an equal basis with others'. This association between people with impairments, barriers and inequality derives from the social interpretation, or social model, of disability ([Oliver, 1990](#)), which defines disability as 'the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' ([Union of the Physically Impaired Against Segregation, 1976](#)). The two models are not synonymous ([Kayess and French, 2008; Kakoullis and Ikehara, 2018](#)) but lead to similar measurement conclusions.

In the context of the CRPD, people with impairments (or 'persons with disabilities') are a minority group of rights holders. To report progress on their equality we must first identify them in the available data and then compare their social participation with other persons in society. This suggests an outcome-oriented approach, such as comparing employment rates or poverty risk between the two groups. The disaggregation of persons 'with' and 'without' impairments (independent variable) is the most controversial step in this process, and much discussed in the literature (for example, [Abberley, 1992; Department of Economic and Social Affairs Statistics Division, 2001; Madans et al, 2011](#)). But there is also a challenge of disaggregation of sub-groups within such a diverse and intersectional population, for example in relation to disabled women and girls, people with different types of impairment, in different generational age groups, and so on.

The equality and human rights paradigm underpinning international disability policy frameworks today is also somewhat at odds with the medical or health paradigms underpinning traditional disability statistics. New policies require new types of evidence. Disability equality indicators require respect for the advocacy claims of the disabled people's movement to 'full participation and equality' and for the CRPD's legal assurance that they have rights to participate in society 'on an equal basis with others'. At a minimum, public authorities should be able to evidence the extent to which disability rights holders enjoy participation outcomes on an equal basis with others. This task, like gender or 'race' equality monitoring, is well suited to the development of quantitative indicators ([Alkire et al, 2009](#)).

Quantification and rights-based advocacy

The application of social scientific methods to human rights is not new (Marie, 1973) but measurement has often proved elusive (Claude and Jabine, 1992), particularly when comparing between countries (Redfern, 1995) and over time (Banks, 1986). There has been a gradual movement towards quantification but practical attempts to measure rights were often hampered by quality of information and conceptual clarity (Stohl et al, 1986), or by lack of focus on reliability and validity (Bollen, 1986). Nevertheless, there is broad consensus that ‘The concept of equality, which pervades internationally defined human rights standards, implies comparison and measurement’ (Claude and Jabine, 1986: 552).

Quantitative methods have not been well developed in the evidence base of disability rights advocacy, or in disability studies, where qualitative sociology and legal scholarship were more prominent (Cosier, 2012). Across the human rights field, the term ‘indicator’ is also used rather loosely to include both criterion-based and measurement-based achievements – to record states’ legal compliance with international rights standards or to measure the progress of rights holders towards more equal outcomes (Green, 2001; De Beco, 2013). Landman and Carvalho (2009) observed a decade ago that all aspects of human rights merit attention to measurement but that less progress had been made in measuring the fulfilment of rights than in the respect for them. For this reason, we focus here on outcome measures.

Some writers are concerned that statistical indicators foster a culture of governing ‘at a distance’ (Rose and Miller, 1992; Davis et al, 2012; Davis, Kingsbury and Merry, 2012) but their advocacy value lies precisely in their indicative character: their capacity to point rights defenders towards potential abuses for deeper local investigation. It is well known that comparisons of international governance are difficult (Hood et al, 2008) and that ‘good enough’ measurements are often needed (Hoffmann and Dooren, 2017). As scientists we strive for the best possible evidence but, as advocates, we make best use of the evidence that is available in the circumstances. For this reason, even indicators that are limited in measurement precision or comparability may prove ‘good enough’ to provide useful pointers for rights defenders in real-world policy contexts. Nevertheless, advocating for minority rights on the basis of quantitative indicators means persuading both rights advocates and policymakers to trust the numbers:

The explosive demand for ‘indicators’ that can be used to determine the degree to which States are living up to their human rights obligations is intimately connected with the trust in data that is understood to be abstract, quantifiable, and putatively transferable. (Rosga and Satterthwaite, 2009: 281)

Related to this is a risk of discursive ‘drift’ (or displacement) in policy debates away from substantive questions of equality and towards technical questions of measurement. For example, a charged political discussion about comparative levels of poverty among disabled people can easily ‘drift’ into a technical discussion about data quality. For example, Hersch and Bullock (2014: 2365) assessed the use of statistical models as evidence in disability discrimination cases before US courts, noting how:

Opposing experts routinely criticize three aspects of the regression: the regression’s explanatory variables, its sample size, and its statistical significance. Even though these factors affect the reliability of the regression results only

in very limited circumstances, the judge or jury is often persuaded by them and find for the defendant.

Serious discussions of validity and reliability are always needed (Adcock and Collier, 2001) but there remain concerns that 'simplified numerical representations of complex phenomena... replace political debate with technical expertise' (Merry, 2011: S83).

Compared to the qualitative, often visceral, reporting of individual rights violations, aggregate indicators can have a distancing effect that is further clouded if there is methodological dispute (although advocacy based on qualitative evidence is as often dismissed by policymakers as anecdote). The key point is that the preparation of evidence-based rights advocacy should minimise the risk of discursive drift from debates about equality to debates about methodology. This means building trust in the validity of data definitions, the reliability of measurements and their comparability.

We take an optimistic view. Even partial evidence of inequalities tends to fuel rather than extinguish the fires of political debate, and the policy impact of statistical indicators often owes as much to their expressive function as to their technical precision. As Merry admits, 'Indicators introduce into the field of global human rights law a form of knowledge production in which numerical measures make visible forms of violation and inequality that are otherwise obscured' (Merry, 2011: S84). Indicators are thus essential in making the rights of marginalised population groups, including disabled people, more visible and governable.

Methods

The research took place between 2008 and 2019, within the wider research programme of the European Commission's Academic Network of European Disability experts (ANED). The aims were to develop 'Indicators of Disability Equality in Europe' and to demonstrate their policy application, including to monitor CRPD implementation in the EU (Priestley and Lawson, 2009; 2013; Priestley and Lawson, 2009). An initial study was commissioned to scope the availability of European comparative data on the situation of disabled people (van Oorschot et al, 2009), followed by feasibility and piloting studies to match data with conceptual indicator proposals (Grammenos, 2009; 2010; 2011).

These studies showed that EU data sources, notably social surveys, offered potential for cross-national comparison of policy-relevant outcomes for disabled people (for example, in relation to education, employment, income and social protection, political or cultural participation, and so on). Nevertheless, there was little evidence that such data had been analysed systematically and there was a lack of harmonisation in its collection. EU data had been used to count disabled persons, in contexts of 'health', but not to evidence social inequalities systematically in a context of rights.

Seven criteria for selection of statistics were considered, that they should: reflect the selected indicators closely; be the result of clear and unambiguous questions; provide comparable results (harmonised methods); be of good statistical quality (sample size, and so on); guarantee collection at regular intervals; cover all EU Member States if possible; and ensure comparison of indicators over time. We prioritised consistency with existing EU policy indices and relevance to the CRPD.

Accordingly, we selected data mainly from the European Statistics on Income and Living Conditions (EU-SILC) but also the European Quality of Life Survey (EQLS), the Survey of Health, Ageing and Retirement in Europe (SHARE), the European

Social Survey (ESS), the European Health Interview Survey (EHIS), the European Health and Social Integration Survey (EHSIS), the Eurobarometer surveys, the Labour Force Survey ad hoc module 2011 on the employment of disabled people, and the European Values Study (EVS). The core EU-SILC survey covers persons aged 16 and over in private households but excludes children and persons living in congregative households (such as residential institutions). Nevertheless, it was the most comprehensive source of annual microdata capable of disability disaggregation, with more than half a million observations obtained mainly from personal interviews.

In line with pilot studies conducted for Eurostat (Grammenos, 1995; Applica et al, 2007), most EU survey data require disaggregating a proxy variable, to identify persons who report ‘limitations’ or ‘difficulties’ associated with long-term ‘health problems’, and then cross-tabulating this with selected participation measures to compare outcomes for that group with outcomes for other persons in the survey (for example, comparing employment rates or poverty rates). In the EU-SILC this means using the Global Activity Limitation Indicator (GALI), which asks: ‘For at least the past six months, to what extent have you been limited because of a health problem in activities people usually do?’. The response options are: ‘severely limited / limited but not severely or / not limited at all’.

This type of wording is conceptually awkward because disability, according to the social model and the CRPD, arises from ‘barriers’ that people with impairments encounter rather than from a health condition directly. In addition, there is a lack of correspondence between respondent perceptions of ‘difficulty’, ‘activity limitation’ and ‘disability’. For example, half of those reporting ‘difficulties’ in at least one physical or sensory domain do not declare a ‘limitation in activities people usually do’. Despite this, GALI performs fairly well against other such measures (Van Oyen et al, 2006; Jagger et al, 2010; Office for National Statistics, 2019; Wilmot, 2020), albeit with wide variation between countries attributed to differences in survey design and implementation, or respondent perception and understanding (Berger et al, 2015). An additional limitation in the available data is that few of the EU surveys allow identification of different impairment or difficulty types within the disability category, as the UN statistical department would recommend (Madans et al, 2011).

Using EU-SILC microdata we disaggregated participation outcomes for people reporting ‘activity limitations’ and compared them with other persons, for the EU and each of its associated countries, every year, from 2008 to 2018 (processing more than five million observations and reporting according to Eurostat standards). We populated indicators for a range of dependent outcome variables relevant to EU policy and CRPD rights. The most relevant for the EU2020 strategy included: employment rate; unemployment rate; activity rate; early leavers from education and training; completion of tertiary or equivalent education; people living in households with very low work intensity; people at risk of poverty after social transfers; severely materially deprived people; and people at-risk-of-poverty or social exclusion (a composite of the previous three indicators). Where possible we disaggregated further (for example, by gender, age or severity of impairment). The limitations encountered in doing this are identified in the example findings.

The second part of the method involved advocacy to promote policy applications of these indicators, in collaboration with European Commission staff. The aim here was to mainstream disability equality measures into EU policy processes, both generic and disability-specific policies. For instance, the above examples were targeted, through

disability-focused country reports, as input to the 'European Semester' process of policy coordination supporting the EU2020 strategy (Priestley, 2012; 2019), within Eurostat and the European Statistical System more widely. This activity included presentations to EU bodies and committees, such as the European Day of Persons with Disabilities conference, Ministerial conferences, the High Level Group on Disability, the European Economic and Social Committee, Eurostat and the Social Protection Committee. Outcomes of both the indicators and the advocacy are summarised in the following findings, in relation to selected CRPD rights.

Findings

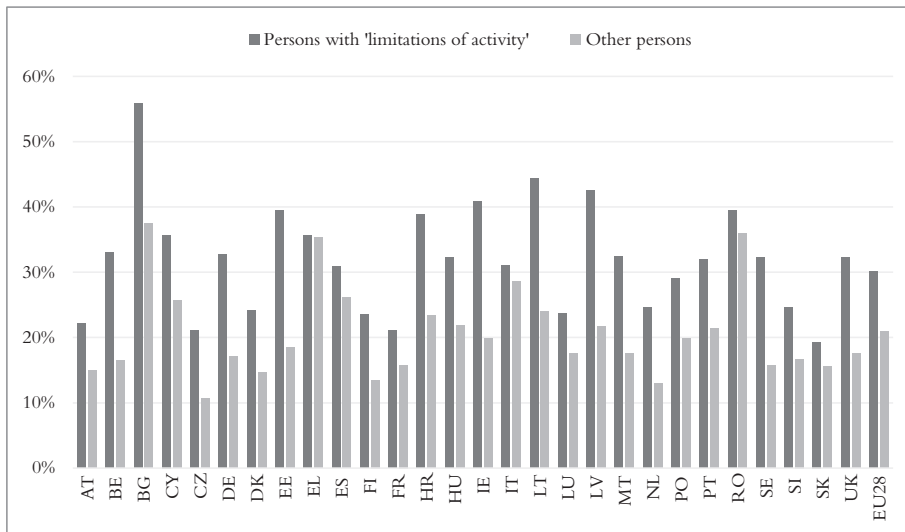
We present two examples that align governance of EU strategy with the CRPD, comparing the challenges of measuring and mainstreaming disability equality indicators of (a) poverty or social exclusion, and (b) employment, education and training. We summarise first the measures and then their adoption in policy systems.

Case study A: adequate standard of living and social protection (Article 28 CRPD)

Article 28 CRPD affirms 'the right of persons with disabilities to an adequate standard of living for themselves and their families', as well as access to social protection programmes, in particular for women and girls and older persons. Appropriate outcome measures ought to include, at least, a disaggregated measure of living standard and social protection for disabled people and their families, with some breakdown by gender and age. Ideally, this might extend to more specific provisions within the Article (like access to 'disability-related expenses' and 'retirement benefits and programmes') but the priority is to indicate gaps in poverty risk between the disability group and other persons in the population, as a baseline to evidence progress in closing this gap.

The CRPD concept of 'adequate standard of living and social protection' proved a good fit with existing EU indicators for the general population. The EU2020 strategy included a headline objective to lift 20 million people out of poverty and social exclusion, supported by an agreed indicator of households 'at risk of poverty or social exclusion' (AROPE). This is a compound indicator of persons either at risk of poverty or severely material deprivation, or living in a household with a very low work intensity (see Eurostat, 2020). There was a well-established procedure for constructing it and the data source (EU-SILC) contained a disability variable capable of disaggregation (GALI).

The disaggregation revealed a consistent equality gap in AROPE between persons declaring 'limitations in activities' and other persons, overall (see Figure 1). For example, the 2018 data indicated that, on average at the EU level, 21.4% of persons aged 16 and over were living in households at risk of poverty or social exclusion, but the disaggregation indicated this risk at 29.2% among people with impairments, compared to 18.9% among other persons. The disability equality gap amounted to 10.3 percentage points and the difference that disability made to the EU's overall progress on poverty reduction was thus 2.6 points (that is, the difference between the official AROPE indicator and the disaggregated rate, excluding persons declaring limitations). From a disability perspective, this might indicate evidence of discrimination/disadvantage arising from encounters with disabling barriers. In an inclusive society,

Figure 1: People living in households at-risk-of-poverty or social exclusion, 2016. Age: 16+

Source: EU-SILC UDB 2018, Percent of persons who are either at risk of poverty or severely materially deprived or living in households with very low work intensity (crude rates)

the average risk of poverty or social exclusion should not be appreciably higher for the minority group of persons than it is for other persons (after controlling for other relevant variables such as gender, age and so on).

Each sub-component of the AROPE indicator, and the contributory effects of employment and social protection systems, including disability benefits, were further analysed in thematic reports (Sainsbury et al, 2016; Grammenos, 2018; Priestley, 2019). In line with Article 28 CRPD, we were able to break down these indicators by gender and age (albeit without data for children under 16), to approximate for severity of impairment (using the GALI response options), and to track these measures over a ten-year period. On each measure risk remained consistently higher for people with activity limitations than for other persons, and it increased with severity. Women remained at higher risk than men, on average, and adults of working age at higher risk than older persons (work intensity plays an important role for younger adults but is not relevant to retired people).

These general patterns were evident also at the national level in each of the EU's Member States. The level of risk, and the gaps, varied considerably between countries but they remained broadly consistent within countries, except when changes in survey methodology caused disruption (such as a change in question wording in Germany in 2015). Variations in AROPE are well known in general (Osier et al, 2013) but might also reflect variations in the independent variable (GALI) as well as variations in the general economic situation (for example, in Greece, Italy or Romania after the financial crisis, where deterioration of the labour market for the general population, coupled with the protective effect of disability pensions, obscured relative gaps for minorities).

Overall, the CRPD concept of 'adequate standard of living and social protection' offered a good fit with the existing EU strategy indicator for 'risk of poverty or social

exclusion'. The production of disability equality indicators was based on the same EU dataset, trusted by Eurostat for this purpose, and its calculation mirrored the established methodology. Disability disaggregation using the GALI variable was unfamiliar in this policy context, introducing an additional element of methodological uncertainty but with acceptable levels of accuracy. Nevertheless, different definitions of disability among the Member States raised further questions for discussion.

Case study B: the right to work and employment (Article 27)

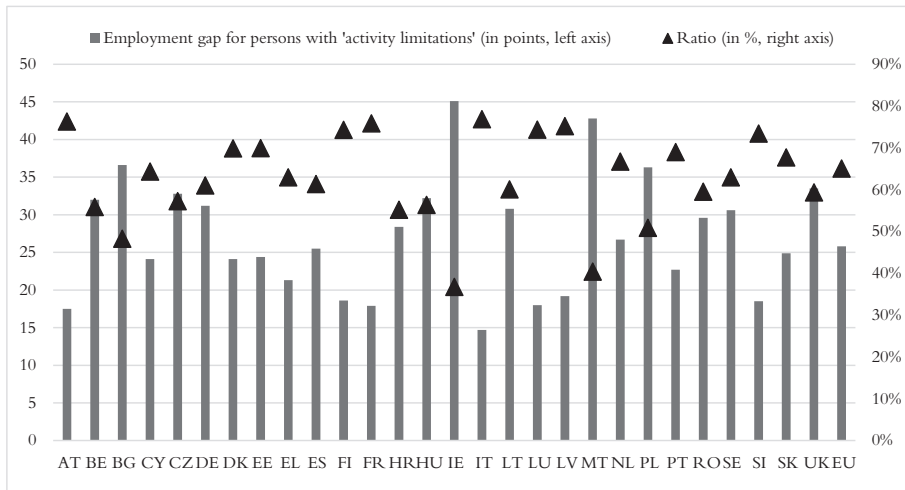
Article 27 CRPD on the right to work and employment provides a useful comparison. It requires that 'States Parties recognize the right of persons with disabilities to work, on an equal basis with others'. Its sub-clauses prohibit discrimination, require the promotion of opportunity, and assure the provision of reasonable adjustments, appropriate support and so on, throughout working careers.

As in the previous case, there was a close policy fit between the CRPD concept and the indicator framework underpinning EU2020, which aimed to reach a general employment rate of 75% among persons aged 20–64, for the EU as a whole (with a specific target for each participating Member State). The indicator was broken down by gender and, along with indicators of educational attainment, calculated using data from the harmonised core of the Labour Force Survey (EU-LFS). This presented a significant problem, as neither the GALI variable nor any other proxy for impairment/disability were included in this survey at the time (although a minority of EU Member States included a defined variable in their national LFS questionnaires). In this regard, disabled people remained statistically invisible. An ad hoc LFS module on employment of disabled people had been administered in 2001 and again in 2011 but, during the period of research, there was no evidential basis on which to disaggregate disability equality indicators annually, using the same method as for the general population (this changes in 2021).

For these reasons it was necessary to construct an alternative indicator from the EU-SILC data, but that survey also formulates a different question concerning employment status than EU-LFS (SILC relies on self-defined economic status based on a list of category options while EU-LFS aligns with International Labour Office definitions of work in a specified reference period). Nevertheless, by disaggregating the SILC data for a comparable working age group using the GALI variable and economic status we were able to produce an estimate of disability employment rates, broken down by gender, on an annual basis. Indicators of unemployment and economic activity were similarly derived. We were also able to compare these estimates with those from LFS modules, to evidence their reliability.

For example, in 2018, the EU-SILC indicated an employment rate for all persons aged 20–64 of 71.8%, while the LFS survey estimated 73.2% (a difference of 1.4 percentage points, with similar differences in other years). Although the LFS presents a consistently higher employment rate than EU-SILC the evolution was strongly correlated at the EU and national level and appeared sufficiently robust to estimate disability equality gaps. On this basis, the data indicated that 52.0% of persons with 'limitations of activity' were employed in 2016 compared to 76.2% of other persons. Accordingly, the employment gap was estimated at 24.3 percentage points and the difference that disability made to the EU's overall progress on its employment goal was around 4.4 points (that is, without improvement in disability employment a rate

Figure 2: Disability employment gaps and ratios (age 20–64), 2018



Source: EU-SILC UDB 2018. Gap = % persons without limitations minus % persons with limitations. Ratio = 100* (persons without limitations divided by % persons with limitations).

of nearly 80% might be needed among other persons to reach the overall EU target of 75%).

On these measures, consistent disability employment gaps were evidenced throughout the decade of research. The gap widened with severity of impairment, for women and for older working age adults. The reliability of national trends among younger age groups was limited, as the reported prevalence of activity limitation is smaller, and this affected also the estimation of related indicators on early school leaving or tertiary educational attainment (Grammenos, 2018). EU-SILC has a smaller sample size than the EU-LFS so the disability employment indicators, produced from it, had higher standard errors. Despite these challenges, the general pattern of employment rates and gaps was replicated in all of the Member States, and for the sub-indicators of unemployment and economic activity throughout the period, but with wide variation between countries (and occasional disruption caused by changes in national definition or implementation). Figure 2 indicates the size of the employment gap in each country in 2018 (in percentage points) and the relative chance of employment for persons declaring ‘limitations’ compared to the other persons (as a percentage).

Overall, the choice of labour market indicators was well suited to the CRPD concept and it had a clear fit with EU strategy indicators for the general population but, in this case, the production of disability equality indicators could not use the established EU dataset or methodology due to the absence of an annual disability proxy variable in EU-LFS. The challenge of mainstreaming disability equality indicators into policy process was therefore amplified, in the employment policy context, by a combination of presenting unfamiliar variables from an unfamiliar dataset and with greater statistical uncertainty. The future inclusion of GALI in the EU-LFS surveys will permit the elaboration of mirrored indicators and its large sample of economically active persons will improve reliability.

Mainstreaming the indicators in policy process

The accumulated evidence base was applied to EU processes through advocacy, by the researchers and in collaboration with civil servants in the European Commission.

In 2009, presentations of the initial findings on employment and social inclusion were invited to the official European Day of Persons with Disabilities and as oral evidence to the European Economic and Social Committee, referenced in the Committee's written Opinion. These findings were used in European Commission staff input to the European Council's Joint Employment Report for 2009/2010 and referenced in the EU Vice-President's address to a ministerial conference of the Hungarian EU Presidency on European Disability Strategy in 2011. In parallel, the evidence was used to underpin the EU's first official Treaty report to the UN CRPD monitoring process, with a report prepared for the EU Council of Ministers and submitted to the UN in 2013.

In 2010, the European Commission drew on the evidence to inform preparation of its Disability Strategy 2010–2020, which then made a commitment to improve EU-level monitoring on disability rights, including the development of statistics and data collection. The aim was 'to streamline information on disability collected through EU social surveys' and to 'present a set of indicators to monitor their situation with reference to key Europe 2020 targets' (European Commission, 2010: 10).

On this basis, in 2012, Eurostat (the EU's statistical office) was persuaded to launch a disability database, including the poverty and social inclusion indicators piloted in the research. Following presentation of the findings, further testing and consultation, the EU Social Protection Committee also adopted a disability indicator in its Social Protection Performance Monitor (SPPM) in 2018. After continued lobbying, Eurostat agreed in 2018 to include a standardised disability variable (GALI) in all its major social surveys, including the EU-LFS, in line with research recommendations.

Collaborative advocacy between the researchers and civil servants was also key to mainstreaming disability equality in the 'European Semester' process supporting policy coordination of the Europe 2020 strategy. This resulted in disability issues being identified in the Commission's annual Country Reports and in Country-Specific Recommendations from the EU to Member States. For example, based on the research data, the Commission's 2020 analytical Country Report to Belgium observed that 'Compared to other countries, people with disabilities are more at risk of poverty or social exclusion' (European Commission, 2020a: 5), and that 'The employment rate of people with disabilities remains well below the EU average' (European Commission, 2020a: 36). Similarly, it reported on Bulgaria that, 'The employment rate of people with disabilities remains one of the lowest in the EU' (European Commission, 2020b: 36), and in Cyprus that, 'The at-risk-of-poverty-or-social exclusion (AROPE) rate for people with disabilities is significantly higher than the EU average' (European Commission, 2020c: 46). Even on education, the reports evidenced that in 'Czechia, 'The early school leaving gap between people with and without disabilities is also one of the highest in the EU' (European Commission, 2020d: 26) or that, 'Among persons with disabilities, the tertiary attainment rate is lower in Germany than the EU' (European Commission, 2020e: 46). Such observations resulted in disability equality being mentioned in the European Council's adopted Country Specific Recommendations to 20 out of 27 Member States in 2020.

In the 2019 Semester cycle, all 28 of the Commission's country analysis reports raised disability issues, twice as many as in 2012. The number of Country-Specific Recommendation fiches referring to disability also rose from three in 2012 to 18 in 2019. As a consequence, visibility in the EU's high-level Joint Employment Report increased from just seven references to disability in 2013 to 57 in 2019 (increasing each year). In this way, indicative disability statistics that had been entirely missing from the mainstream of EU policy began to make disability visible in its coordination. In 2017, the Commission's Progress Report on the European Disability Strategy identified this 'Mainstreaming of disability issues in the European Semester process and policy publications' as one of its 'Main progress' achievements since 2010, highlighting the research evidence base. It is interesting to observe that this policy mainstreaming proceeded largely irrespective of the evident statistical limitations in the comparability of different measures.

Discussion and conclusions

Power knowledge relationships are important in the process of indicator development, as in any process of policy formation. Rights-based indicators are important in holding states to account for their policies, and providing a benchmark against which communities can measure progress, but their conceptualisation has not always been clear (Raworth, 2001). As Merry (2011: S84) put it, 'indicators typically conceal their political and theoretical origins and underlying theories of social change and activism'. For this reason, an ethnographic or genealogical approach to understanding the creation of numerical indicators allows the political contingencies of their production and measurement choices to be made visible too. Rights defenders need to understand more about the data quality concerns of statistical authorities and those authorities need to understand more about the conceptualisation of rights-based indicators.

The two case studies illustrate some of the challenges facing evidence-based advocates of minority group rights. The first example showed how public investment in data collection is not always matched by public efforts to disaggregate and publish minority indicators. The second example showed how lack of disaggregated data collection impedes the development of equality indicators. In both cases this resulted in the invisibility of disability issues in policy process. A sustained intervention to populate equality indicators, and to advocate strongly for them, resulted in increased visibility and governance of disability issues. The methodological vulnerability of some measures, or their unfamiliarity, generated some resistance in policy discussions but, in this policy context at least, even 'imperfect' indicators proved 'good enough' to impact on rights recognition.

The findings highlight the patchy availability of disability data in the EU and gaps in its alignment with evidence-based policy process. More public investment has been secured in data collection, but more is needed in data quality. At the same time, a bold approach is needed to exploit as yet imperfect data in advocating for disability rights (and for other minority group rights too). The act of measuring outcomes imperfectly provides normative pointers that are often 'good enough' to make a real difference in policy process, and it is only by demonstrating what can be measured that commitments to do it better are secured.

The expressive function of indicators

The findings suggest that measuring inequalities has an expressive function as well as a technical function. This idea is familiar from legal scholarship on human rights (for example [Ellickson, 1994](#); [Lessig, 1995](#); [Geisinger, 2002](#)). For instance, [Sunstein \(1999; 1996\)](#) characterises expressive law as 'making statements' that are capable of changing social norms in society. [Geisinger and Stein \(2007: 78\)](#) applied this to human rights treaties, showing how international community and 'reputational mechanisms' influence states to enter commitments and comply with rights norms (see also [Hathaway, 2005](#)). Quantitative indicators offer a similar reputational mechanism of norms (for example, via rankings or comparisons). The publication of disability equality indicators in a trans-national policy context like the EU has a strong 'expressive function' reinforcing human rights norms and highlighting deviations from them – collectively or among particular sub-groups.

There are further parallels between the expressive function of human rights law and of rights-based indicators. [McGinn \(2015: 1\)](#) invokes the antiquated concept of *lex imperfecta* to describe a kind of 'unfinished' law, that discourages certain behaviours while lacking the legal completeness to enforce them definitively. [Reisman \(1981\)](#) characterises international law in this way – as a communicative process, lacking precise closure but still affecting state behaviour (for example [Wittlin, 2011](#)). This sums up the current status of international law in the disability field. The CRPD offers a strong normative framework and monitoring its implementation comparatively invokes a reputational mechanism for compliance. Just as 'unfinished' laws have an expressive function in legal advocacy so 'indicative' statistics have an expressive function in evidence-based advocacy – what we might call *stat imperfecta*.

Human rights advocates have been creative in their interpretation of imperfect legal means to defend moral ends, but the logic of statistical authorities tends in the opposite direction (they are, after all, the defenders of public trust in technical means over social ends). This means that, even where indicative statistics are 'good enough' to evidence systematic inequalities for minority groups, they are not always precise enough (or trusted enough) to enter the official evidence base on which formal policy processes are based. The examples of indicator developments in which we have been involved over the past decade in Europe illustrate this.

Charting the now familiar range of concerns about concept definition, data availability, reliability, and comparability, [Goldstein \(1986: 627\)](#) concluded that:

... despite all of the limitations... concerning the difficulty of using and obtaining good human rights data in the political field for scholarly purposes, in many cases even incomplete data or data which do not lend themselves to comparative purposes can still serve a helpful public education and public policy function.

It is this function that often drives the deployment of numbers by rights advocates in policy debates, but they are not always trusted by those to whom they are directed. The public validation of equality statistics, such as their adoption within the EU statistical system, is an important form of rights recognition. It enables inequalities to become more visibly governed and more publicly accountable to communities and in policymaking. Prior to our research, a lack of authoritative disability equality data resulted in the inequalities experienced by disabled people remaining largely

invisible and unaccountable in key EU policy processes – a deficiency we sought to challenge.

Whenever we encounter resistance to rights-based measurement we should ask whether this reflects lack of technical feasibility or lack of political will. When a statistically weak measure hints at a strong message there may be reason to invest more effort in its measurement, not less. The choices that states make to measure outcomes for some groups rather than others is an expressive statement about their respective rights recognition of those groups. We should be prepared to judge the effort states make to measure inequalities, as well as the precision they achieve in doing so. If a right is worth defending then its achievement is also worth measuring.

Conflict of interest

The authors declare that there is no conflict of interest.

References

- Abberley, P. (1992) Counting us out: a discussion of the OPCS disability surveys, *Disability, Handicap & Society*, 7(2): 139–55. doi: [10.1080/02674649266780171](https://doi.org/10.1080/02674649266780171)
- Adcock, R. and Collier, D. (2001) Measurement validity: a shared standard for qualitative and quantitative research, *American Political Science Review*, 95(3): 529–46. doi: [10.1017/S0003055401003100](https://doi.org/10.1017/S0003055401003100)
- Alkire, S., Bastagli, F., Burchardt, T., Clark, D., Holder, H., Ibrahim, S., Munoz, M., Terrazas, P., Tsang, T. and Vizard, P. (2009) *Developing the Equality Measurement Framework: Selecting the Indicators*, Manchester: Equality and Human Rights Commission.
- Altman, B.M. (2001) Disability definitions, models, classification schemes, and applications, in G.L. Albrecht, K. Seelman and M. Bury (eds) *Handbook of Disability Studies*, London: SAGE, pp 97–122.
- Altman, B.M. (2014) Definitions, concepts, and measures of disability, *Annals of Epidemiology*, 24(1): 2–7. doi: [10.1016/j.annepidem.2013.05.018](https://doi.org/10.1016/j.annepidem.2013.05.018)
- Applica, CESEP and Alphametrics (2007) *Men and Women with Disabilities in the EU: Statistical Analysis of the LFS ad hoc Module and the EU-SILC*, Brussels: DG Employment, Social Affairs and Equal Opportunities.
- Banks, D.L. (1986) The analysis of human rights data over time, *Human Rights Quarterly*, 8(4): 654. doi: [10.2307/762197](https://doi.org/10.2307/762197)
- Berger, N., Van Oyen, H., Cambois, E., Fouweather, T., Jagger, C., Nusselder, W. and Robine, J.M. (2015) Assessing the validity of the global activity limitation indicator in fourteen European countries, *BMC Medical Research Methodology*, 15(1): 1. doi: [10.1186/1471-2288-15-1](https://doi.org/10.1186/1471-2288-15-1)
- Bollen, K.A. (1986) Political rights and political liberties in nations: an evaluation of human rights measures, 1950 to 1984, *Human Rights Quarterly*, 8(4): 567. doi: [10.2307/762193](https://doi.org/10.2307/762193)
- Claude, R.P. and Jabine, T.B. (1986) Symposium: statistical issues in the field of human rights, *Human Rights Quarterly*, 8(4): 551–66. doi: [10.2307/762192](https://doi.org/10.2307/762192)
- Claude, R.P. and Jabine, T.B. (1992) *Human Rights and Statistics: Getting the Record Straight*, Philadelphia, PA: University of Pennsylvania Press.
- Committee on the Rights of Persons with Disabilities (CRPD) (2009) *Guidelines on Treaty-specific Document to be Submitted by States Parties Under Article 35, Paragraph 1, of the Convention on the Rights of Persons with Disabilities*, Geneva: CRPD.

- Cosier, M. (2012) 'The road less traveled': combining disability studies and quantitative analysis with medium and large data sets, *Research and Practice for Persons with Severe Disabilities*, 37(2): 81–88.
- Davis, K., Fisher, A., Kingsbury, B. and Merry, S.E. (2012) *Governance by Indicators: Global Power Through Classification and Rankings*, Oxford: Oxford University Press.
- Davis, K., Kingsbury, B. and Merry, S.E. (2012) Indicators as a technology of global governance, *Law & Society Review*, 46(1): 71–104.
- De Beco, G. (2013) Human rights indicators: from theoretical debate to practical application, *Journal of Human Rights Practice*, 5(2): 380–97. doi: [10.1093/jhuman/hut003](https://doi.org/10.1093/jhuman/hut003)
- Department of Economic and Social Affairs Statistics Division (2001) *Guidelines and Principles for the Development of Disability Statistics*, New York: United Nations.
- Ellickson, R.C. (1994) *Order Without Law*, Cambridge, MA: Harvard University Press.
- European Commission (2010) *European Disability Strategy 2010–2020: A Renewed Commitment to a Barrier-Free Europe COM(2010) 636 final*, Brussels: European Commission.
- European Commission (2020a) *Commission Staff Working Document: Country Report Belgium 2020*, SWD(2020) 500 final. <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52020SC0500>.
- European Commission (2020b) *Commission Staff Working Document: Country Report Bulgaria 2020*, SWD(2020) 500 final. <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52020SC0501>.
- European Commission (2020c) *Commission Staff Working Document: Country Report Cyprus 2020*, SWD(2020) 512 final. <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52020SC0512>.
- European Commission (2020d) *Commission Staff Working Document: Country Report Czechia 2020*, SWD(2020) 500 final, available at: <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52020SC0502>.
- European Commission (2020e) *Commission Staff Working Document: Country Report Germany 2020*, SWD(2020) 500 final. <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52020SC0504>
- Eurostat (2020) EU statistics on income and living conditions (EU-SILC) methodology – Europe 2020 target on poverty and social exclusion: statistics explained, [https://ec.europa.eu/eurostat/statistics-explained/index.php/EU_statistics_on_income_and_living_conditions_\(EU-SILC\)_methodology_-_Europe_2020_target_on_poverty_and_social_exclusion](https://ec.europa.eu/eurostat/statistics-explained/index.php/EU_statistics_on_income_and_living_conditions_(EU-SILC)_methodology_-_Europe_2020_target_on_poverty_and_social_exclusion).
- Geisinger, A. (2002) A belief change theory of expressive law, *Iowa Law Review*, 88(1): 35.
- Geisinger, A. and Stein, M.A. (2007) A theory of expressive international law, *Vanderbilt Law Review*, 60(1): 75.
- Goldstein, R.J. (1986) The limitations of using quantitative data in studying human rights abuses, *Human Rights Quarterly*, 8(4): 607–27. doi: [10.2307/762195](https://doi.org/10.2307/762195)
- Grammenos, S. (1995) *Disabled Persons Statistical Data 1993*, Luxembourg: Office for Official Publications of the European Communities.
- Grammenos, S. (2009) *Indicators of Disability Equality in Europe Feasibility Study: an Evaluative Report on the Feasibility of Using Existing Data Sources*, Utrecht/Leeds: Academic Network of European Disability experts (ANED).

- Grammenos, S. (2010) *Indicators of Disability Equality in Europe: Preliminary List of Comparative Indicator Items for Pilot*, Utrecht/Leeds: Academic Network of European Disability experts (ANED).
- Grammenos, S. (2011) *IDEE - Indicators of Disability Equality in Europe: Update and Extend the Piloting of Quantitative Implementation Indicators, Comparative Data on A Selection of Quantitative Implementation Indicators*, Utrecht/Leeds: Academic Network of European Disability experts (ANED).
- Grammenos, S. (2018) *European Comparative Data on Europe 2020 & People with Disabilities*, Utrecht/Leeds: Academic Network of European Disability experts (ANED).
- Green, M. (2001) What we talk about when we talk about indicators: current approaches to human rights measurement, *Human Rights Quarterly*, 23(4): 1062–97. doi: [10.1353/hrq.2001.0054](https://doi.org/10.1353/hrq.2001.0054)
- Hathaway, O.A. (2005) Between power and principle: an integrated theory of international law, *University of Chicago Law Review*, 72(2): 469–536.
- Hersch, J. and Bullock, B.D. (2014) The use and misuse of econometric evidence in employment discrimination cases, *Washington and Lee Law Review*, 71(4): 2365.
- Hoffmann, C. and Dooren, W.V. (2017) Towards good enough measurement: sick leave statistics as a case of the measurement challenges in comparative public performance, *Journal of Comparative Policy Analysis: Research and Practice*, 19(4): 362–76. doi: [10.1080/13876988.2015.1122153](https://doi.org/10.1080/13876988.2015.1122153)
- Hood, C., Dixon, R. and Beeston, C. (2008) Rating the rankings: assessing international rankings of public service performance, *International Public Management Journal*, 11(3): 298–328. doi: [10.1080/10967490802301286](https://doi.org/10.1080/10967490802301286)
- Jagger, C., Gillies, C., Cambois, E., Van Oyen, H., Nusselder, W., Robine, J.M. and Team, E. (2010) The global activity limitation index measured function and disability similarly across European countries, *Journal of Clinical Epidemiology*, 63(8): 892–99. doi: [10.1016/j.jclinepi.2009.11.002](https://doi.org/10.1016/j.jclinepi.2009.11.002)
- Kakoullis, E. and Ikehara, Y. (2018) Article 1 purpose, in I. Bantekas, M. Stein and D. Anastasiou (eds) *The Convention on the Rights of Persons with Disabilities: A Commentary*, Oxford: Oxford University Press.
- Kayess, R. and French, P. (2008) Out of darkness into light? Introducing the convention on the rights of persons with disabilities, *Human Rights Law Review*, 8(1): 1–34. doi: [10.1093/hrlr/ngm044](https://doi.org/10.1093/hrlr/ngm044)
- Landman, T. and Carvalho, E. (2009) *Measuring Human Rights*, London: Routledge.
- Lawson, A. and Priestley, M. (2009) *Monitoring the Implementation of the UN Convention on the Rights of Persons with Disabilities in Europe: Principles for the Identification and Use of Indicators*, Utrecht/Leeds: Academic Network of European Disability Experts (ANED).
- Lawson, A. and Priestley, M. (2013) Potential, principle and pragmatism in concurrent multinational monitoring: disability rights in the European Union, *International Journal of Human Rights*, 17(7–8): 739–57. doi: [10.1080/13642987.2013.834494](https://doi.org/10.1080/13642987.2013.834494)
- Lessig, L. (1995) The regulation of social meaning, *University of Chicago Law Review*, 62(3): 943–1045. doi: [10.2307/1600054](https://doi.org/10.2307/1600054)
- Madans, J.H., Loeb, M.E. and Altman, B.M. (2011) Measuring disability and monitoring the UN convention on the rights of persons with disabilities: the work of the Washington group on disability statistics, *BMC Public Health*, 11(4), doi: [10.1186/1471-2458-11-4](https://doi.org/10.1186/1471-2458-11-4)

- Marie, J.B. (1973) Une methodologie pour une science des droits de l'homme, *Revue des Droits de l'Homme*, 6(1).
- McGinn, T.A. (2015) The expressive function of law and the *lex imperfecta*, *Roman Legal Tradition*, 11: 1–41.
- Merry, S.E. (2011) Measuring the world: indicators, human rights, and global governance, *Current Anthropology*, 52(Suppl3): S83–S85. doi: [10.1086/657241](https://doi.org/10.1086/657241)
- Office for National Statistics (ONS) (2019) *Measuring Disability: Comparing Approaches*, London: ONS.
- Oliver, M. (1990) *Politics of Disablement*, London: Macmillan.
- Osier, G., Berger, Y.G. and Goedeme, T. (2013) *Standard Error Estimation for the EU-SILC Indicators of Poverty and Social Exclusion*, Luxembourg: Eurostat.
- Priestley, M. (2012) Disability policies and the open method of coordination, in G. Quinn and L. Waddington (eds) *European Year Book on Disability Law*, pp 7–34.
- Priestley, M. (2019) *Mainstreaming Disability Equality in the European Semester 2019–20 Policy-issues-and-questions*, Utrecht/Leeds: ANED.
- Priestley, M. and Lawson, A. (2009) *Indicators of Disability Equality in Europe (IDEE): A Preliminary List of Indicator Proposals for Discussion*, Utrecht/Leeds: Academic Network of European Disability experts.
- Raworth, K. (2001) Measuring human rights, *Ethics & International Affairs*, 15(1): 111–31.
- Redfern, P. (1995) Measuring human rights, in M. Desai and P. Redfern (eds) *Global Governance: Ethics and Economics of the World Order*, London: Pinter, pp 94–132.
- Reisman, W.M. (1981) International lawmaking: a process of communication, the Harold D. Lasswell Memorial Lecture, *Proceedings of the ASIL Annual Meeting*, Cambridge: Cambridge University Press, pp 101–20. doi: [10.1017/S0272503700031918](https://doi.org/10.1017/S0272503700031918)
- Rose, N. and Miller, P. (1992) Political power beyond the state: problematics of government, *British Journal of Sociology*, 43(2): 173–205. doi: [10.2307/591464](https://doi.org/10.2307/591464)
- Rosga, A. and Satterthwaite, M.L. (2009) The trust in indicators: measuring human rights, *Berkeley Journal of International Law*, 27(2): 253–315.
- Sainsbury, R., Lawson, A. and Priestley, M. (2016) *Social Protection for Disabled People in Europe: Synthesis Report*, Utrecht/Leeds: ANED.
- Stohl, M., Carleton, D., Lopez, G. and Samuels, S. (1986) State violation of human rights: issues and problems of measurement, *Human Rights Quarterly*, 8(4): 592. doi: [10.2307/762194](https://doi.org/10.2307/762194)
- Sunstein, C.R. (1996) On the expressive function of law, *University of Pennsylvania Law Review*, 144(5): 2021–53. doi: [10.2307/3312647](https://doi.org/10.2307/3312647)
- Sunstein, C.R. (1999) Law's expressive function, *The Good Society*, 9(2): 55–61.
- Union of the Physically Impaired Against Segregation (1976) *Fundamental Principles of Disability: Being a Summary of the Discussion Held on 22nd November, 1975 and Containing Commentaries from Each Organisation*, London: Union of the Physically Impaired Against Segregation.
- Van Oorschot, W., Balvers, M., Schols, M. and Lodewijks, I. (2009) *European Comparative Data on the Situation of Disabled People: An Annotated Review*, Utrecht/Leeds: ANED.
- Van Oyen, H., Van der Heyden, J., Perenboom, R. and Jagger, C. (2006) Monitoring population disability: evaluation of a new global activity limitation indicator (GALI), *Sozial-und Präventivmedizin*, 51(3): 153–61.

- Verdun, A. and Zeitlin, J. (2018) Introduction: the European Semester as a new architecture of EU socioeconomic governance in theory and practice, *Journal of European Public Policy*, 25(2): 137–48. doi: [10.1080/13501763.2017.1363807](https://doi.org/10.1080/13501763.2017.1363807)
- Wilmot, A. (2020) Measuring disability equality in Europe: design and development of the European health and social integration survey questionnaire, in Beatty, P., Collins, D., Kaye, L., Luis, J., Padilla, Willis, G. and Wilmot, A. (eds) *Advances in Questionnaire Design, Development, Evaluation and Testing*, 545–70, <https://doi.org/10.1002/9781119263685.ch22>.
- Wittlin, M. (2011) Buckling under pressure: an empirical test of the expressive effects of law, *Yale Journal on Regulation*, 28(2): 419.