

# The role of civil society in disability data collection: Challenges at EU and national level

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## Abstract

The Work Forum on the implementation of the United Nations Convention on the Rights of Persons with Disabilities met in Brussels on 29 April 2015. The Forum brought together representatives of those responsible for implementing and monitoring the implementation of the UN Disability Convention, both at European and national level; these are focal points, coordination mechanisms and monitoring mechanisms. Civil society and disabled people's organizations also actively participate in the Work Forum. The Work Forum aimed at ensuring that the disability treaty is fully implemented. It allowed to share experiences on its practical implementation and monitoring and to promote solutions to common challenges. It is organized by the European Commission and meets every year since 2010. The implementation of the UN Convention is a shared task: both the European Commission and the vast majority of its Member States are parties to the disability rights treaty and they implement it within their respective competences. Within the frame of the Forum, a roundtable was organized with the theme: "Improving synergies between the EU and the national level in the implementation of the UN Convention". Discussants included the author, Lucian Agafitei from Eurostat and Roberta Cialesi from the National Statistical Authority of Italy (Istat). The following text summarizes the author's remarks and contributions to this discussion, highlights challenges in data collection on disability and advocates for a more active role of civil society in policy surveillance and monitoring.



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Chair, distinguished panelists and delegates, civil society colleagues, ladies and gentlemen,

It is an honor to address such a distinguished group in this year's Work Forum on the Implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). I would like to thank the European Commission for the invitation to speak today about the role of civil society in strengthening the efforts for the collection of accurate and reliable data on disability as well as the challenges associated with the selection and development of indicators for monitoring the implementation of the disability treaty at European and national level. In light of the United Nations CRPD Committee's focus this year on the achievements and challenges of the European Commission's policies for people with disabilities, it's very opportune to reflect on how far we have come in terms of collecting and using disability statistics, as well as what still remains to be done to ensure that the European Union (EU) and Member States have a really robust accountability framework with disabled people's rights at its centre.

## A NEW APPROACH TO DISABILITY RIGHTS MONITORING AND DATA COLLECTION: MORE INCLUSIVE WITH A FOCUS ON ENVIRONMENTAL BARRIERS AND SUPPORTS TO PARTICIPATION

In 2009, when the targets and indicators were being developed to measure the implementation of the European Disability Strategy 2010-2020, disability human rights were not exactly at the forefront of the

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consciousness of those who formulated the indicators. This was not only because the EU at that time has not ratified the CRPD. A key impediment was the lack of available, comparable disability statistics on many of the critical issues that are central to achieving the rights and obligations stipulated in the CRPD, including barriers to accessibility and personal mobility, political participation, education, health and rehabilitation at the national level, among others.

However, we should all recognize that since the EU has ratified the CRPD in 2010, European Institutions have intensified their efforts to revise their thinking and acting on disability, their analyses, models and recommendations about disability policy. The approach on disability policy development has become more inclusive and transparent in accordance with the Convention which requires signatories to ensure the active and meaningful participation of people with disabilities in all matters that concern them (United Nations General Assembly 2012). The European Commission lead this transformation with the help of the civil society, especially the European Disability Forum (EDF) but also other valuable partners such as the Academic Network of European Disability Experts (ANED) who were instrumental in developing the on line statistical information tool of the Commission, the DOT-COM (Priestley and Lawson 2015). So, we are now beginning to see concrete results of the efforts to strengthen States' capacity to monitor the CRPD with the active involvement of civil society.

We are also seeing changes in the collection of data about disability. At the global level, the new Model Disability Survey of the World Health Organization (WHO) places environmental factors on centre stage, recognizing that individual capacities cannot tell the whole story about disabled people's participation and inclusion in society (World Health Organization 2014). The "deficit approach" to measuring disability in social and epidemiological surveys is now being replaced by a more progressive "functional approach" which recognizes the disabling effect of the environment on people's life. Through the use of the International Classification of Functioning, Disability and Health (World Health Organization 2001), WHO attempts to measure and compare where countries stand on a range of priority issues for disability policy such as health, education and social participation – the things that matter most to people with disabilities. This survey which has been piloted tested in countries of the Latin America region covers almost 70% of the data requirements for monitoring the implementation of the CRPD.

Inspired by this new mind-set Eurostat has also developed a disability module for the European Health and Social Integration Survey which has been piloted tested in 10 Member States in 2013. The variables and questions are based on the text of the ICF and reflect the interactive nature of the description of disability contained in the CRPD. The data cover twelve sections including socio-demographic data – health, mobility and transport, education and training, employment, internet use, social contact and support and economic life.

In addition, several civil society organizations ranging from academic institutions to disabled people's organizations have been working on all fronts of disability policy assessment to level the playing field and help their countries focus on measuring environmental barriers and supports. Let me highlight a few key initiatives that illustrate the valuable role of civil society actors in data collection and disability rights monitoring:

1. The Zero Project has a global focus and provides a platform where the most innovative and effective solutions to problems that persons with disabilities face, are shared. Their website contains more than 150 innovative policies and practices on a range of human rights topics and the research of over 30 Social Indicators that help decipher the current global situation on disability (The Zero Project 2016).
2. G3ict – the Global Initiative for Inclusive Information and Communication Technologies – is an advocacy initiative launched in December 2006 by the United Nations Global Alliance for ICT and Development, in cooperation with the Secretariat for the Convention on the Rights of Persons with Disabilities at UN DESA. G3ict's key constituents include policy makers and public sector institutions, organizations of persons with disabilities, ICT industries, the private sector, international standards

development organizations and academia. G3ict supports policy makers with capacity building programs and benchmarking. Deliverables include the online "ITU-G3ict e-Accessibility Policy Toolkit for Persons with Disabilities" and the "CRPD 2013 ICT Accessibility Progress Report," developed in collaboration with Disabled People's International (DPI) as well as a toolkit with key indicators on ICT accessibility (Dion, Pineda, and Ginnerup 2015).

3. At the national level, the Danish Institute for Human Rights and the Danish National Centre for Social Research are working together to identify a set of 10 gold statistical outcome indicators to measure the implementation of the CRPD in Denmark. The Gold indicators aim at building consensus on the main goals regarding the implementation of the CRPD and a motivation for measuring progress in achieving these goals. A well-chosen set of 10 indicators will provide an overview of the overall level of enjoyment of human rights of persons with disabilities.(Larsen 2015)

4. ITHACA (Institutional Treatment, Human Rights and Care Assessment) is a project funded by the European Commission and organized by mental health professionals, lawyers, service users, researchers and social scientists. It aims to document the range of experiences of people with mental illness across Europe. The collaborative efforts of 15 organizations involved in ITHACA produced a monitoring toolkit based on the CRPD. The tool has been used to collect data from 13 EU countries and the findings from these monitoring visits have been used by local and international advocacy groups as evidence for lobbying and initiating change within the systems which produce human rights violations (Randall et al. 2013). Within the area of health, the DREAM project which has been also funded by the Research Executive Agency of the EU, aims to develop rights based indicators for rehabilitation services and programmes to monitor the implementation of Article 25 and 26 of the CRPD (Skempes and Bickenbach 2015).

5. European Deafblind Indicators: This is a project of the European Deafblind Network (EdbN) which aims to create a common European framework for the assessment of institutional models of care for the deafblind based on indicators created ex novo: the Indicators of Deafblindness Equality in Europe (IDbEE) (European Deafblind Network 2014).

The efforts mentioned above helped galvanize attention and action around the world, and progress has been made towards strengthening the collection of disability data although we still have to accelerate achievement in this area to produce data that fulfill the criteria of objectivity, reliability and comparability.

#### **DATA COLLECTION AND INDICATORS FOR MONITORING THE CRPD: NECESSARY BUT PROBLEMATIC**

In thinking about data collection and human rights indicators pertinent to the CRPD we should consider the following challenges:

#### **LEGAL CHALLENGES: THE PROGRESSIVE NATURE OF THE OBLIGATION TO COLLECT DATA**

Firstly, the current indicators and reporting systems at EU or national level may not be adapted or adequate for monitoring the realization of human rights of people with disabilities. For many aspects of the CRPD, States must develop new indicators, especially compliance indicators, and invest significant resources to acquire the data necessary to populate such indicators. Such information may often be of qualitative nature and will be used to complement existing socioeconomic statistical indicators. Events based data are also necessary to capture human rights violations such as disability discrimination. The Committee on the Rights of Persons with Disabilities fails to address this reality in their comments and concluding observations. It is important however to acknowledge that the obligation of States under Article 31 is resource dependent thus progressive. This means that a complete picture of the situation of people with disabilities at EU or national level will become available as financial and knowledge resources become available to the country. People with disabilities as experts of their own situation and condition can expedite the process of knowledge creation by sharing their data and experiences and providing other stakeholders valuable insights about data and information relevant for treaty

monitoring.

### **INSTITUTIONAL CHALLENGES: PARTICIPATION OF CIVIL SOCIETY IN PRIORITIZATION OF MONITORING MEASURES AND TYPES OF DATA TO BE COLLECTED**

In light of resource constraints, and the need to advance an understanding of disability as an evolving concept, the recommendations of supra-national authorities or treaty monitoring bodies should include a directive to Member States to prioritize the types of data and information they should collect in light of the issues that are of particular concern to their jurisdiction. I personally consider the absence of such guidance as the most pressing challenge. This action is also necessary given the severe financial problems faced by several EU Member States. While States and the European Union enjoy significant discretion as to the measures they are using for monitoring the implementation of the CRPD, this should be subject to the caveat that their decisions about data collection and indicators are based on consultations with all relevant actors including people with disabilities and their representative organizations, researchers and academics, community leaders and NGOs. In this regard it is worth noting that many DPOs have expressed complaints of not being included in decisions about data collection in their respective countries as for example the Swedish Disability Federation.

### **THEORETICAL AND SCIENTIFIC CHALLENGES: SHIFTING THE CENTER OF GRAVITY FROM THE PERSON TO THE ENVIRONMENT**

In addition to the obligation of States to collect appropriately disaggregated statistical data on disability, Article 31:2 requires that the information collected should help States “to identify and address barriers faced by persons with disabilities in exercising their rights.”(United Nations 2006) For many of us, either working for international agencies, national institutions or civil society organizations it represents a challenge to develop those metrics that truly address the barriers faced by people with disabilities in many life dimensions and can at the same time be effectively utilized to monitor the state of implementation of the disability treaty. This means going beyond measuring a person's individual capacities alone, and demands that we think again about the factors and conditions that impede or facilitate people's participation and inclusion in all aspects of social, political and economic life. While the ICF provides a useful classification schema, additional research is needed to understand the theoretical foundations for the measurement of the environment (Magasi et al. 2015). The question of what and how to measure the environment goes far beyond the classic categorization of the environmental aspects as barriers or facilitators to social participation (Philibert, Pampalon, and Daniel 2015). I will not go into details with regard to the scientific challenges associated with collecting data on the environment. Other members of the panel are most suitable to address this and I am sure you will hear more about this.

### **MOVING FORWARD WITH AND FOR PEOPLE WITH DISABILITIES – POTENTIAL SOLUTIONS**

Before I close my speech, I would like to give some food for thought with regard to what needs to be done to address the challenges I mentioned before and strengthen Member States monitoring efforts.

First of all, we need a dedicated collaborative structure to build monitoring capacities of national institutions and civil society actors. To address the challenge of progressive realization we need to expedite knowledge creation and build capacity of monitoring institutions and actors. This will require a range of measures and the combination of resources. The EU has established the European Monitoring Framework with the participation of civil society which is responsible for monitoring the CRPD. However, this mechanism does not have the capacity to undertake technical work, conduct research, develop indicators and make policy recommendations. Even if we had the best indicators, these would not lead to policy improvement unless they are used in day to day policy making process. For this reason Europe urgently needs to design a central hub of information, a policy evidence warehouse to ensure that all insights gained from scientific research and other monitoring activities through indicators are translated into evidence based recommendations and better policies.

This would have two advantages: first, exchange knowledge and share information and best practice

on disability rights measurement issues; and second, create more robust expectations for the civil society sector. Such a response could be most effectively delivered through an Observatory on Disability Policy which is more open and transparent as opposed to the ANED and would allow for the participation of civil society organizations, expert institutions and individuals outside academia in its structure and operations. This requires resources but its absence may be more costly to society.

We also need to strengthen participatory scientific research. Civil society including the academic community has certainly an important role to play in improving the situation. Article 31 expressly stipulates that Governments should collect appropriate data for monitoring the CRPD including research data. There is no doubt that we need to strengthen research and encourage the active participation of people with disabilities in research efforts to develop and test methodologies to measure what matters most to their lives. As HORIZON 2020, the flagship initiative of the European Union for research moves on, Member States should encourage and empower disabled people's organizations and academics to develop a common research agenda for the future and engage in resource mobilization activities. This may require coordination at the EU level.

Finally, we need an open platform for deliberative, multi-stakeholder dialogue.

Eurostat has been a successful standard-setter for many years and has developed a wealth of experience and best practice in monitoring the life situation of European citizens. But integrating international human rights law into existing indicator systems requires a multi-stakeholder debate on the way forward. Civil society should be consulted about statistics and indicators not because international human rights law requires so, but because we work smarter when we work together.

So, the question is what kind of regional co-operation could be helpful within the frame of existing EU regulations and legal framework. It would be unrealistic to expect concrete benefits in monitoring the CRPD in the short time given the large fragmentation of financial, human and knowledge resources in this area. So we have to structure a discussion to see which activities could lead to the greatest benefits, which forums already exist for such discussions, how resources can be more efficiently combined to produce tangible results and finally what should be the elements that the Commission, the Member States, the civil society and the private sector wish to co-operate on or coordinate to move forward.

*Delegates, ladies and gentlemen,*

Civil society's role in human rights monitoring is too important to be overlooked. I believe that with continued political will and collaboration Europe can accelerate its efforts to ensure that the disability issues that really matter get measured and that we have the right baselines in place for the post Millennium Development Goals era, so that the data revolution we envision is in fact a disability data revolution. Thank you.

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