

Presentation by Dr Hywel Ceri Jones to the Seminar organised by the Gulbenkian Foundation in Lisbon on December 2009. on disability rights in the European Union

Disability Rights on the European Agenda

This seminar is one of a number of meetings taking place this week in several European Countries to mark European Disability Day, and to draw public attention to the significance of recent policy developments in this field. For this reason too, my other colleagues from the European Consortium , most especially Miguel Cabra de Luna of the ONCE Foundation, my co-chair and the driving force behind this initiative, regrettably cannot be with us today as they are actively representing the Consortium in other European cities.

It is nevertheless a great pleasure for me, as one of the two co-chairs of the Consortium, to be here again in Lisbon and to renew collaboration with friends and colleagues from the Gulbenkian Foundation, which is also one of the founding members of the European Consortium.

Background about the Consortium's aims

The Consortium is hosted by the European Foundation Centre, which is based in Brussels It brings together a group of leading European foundations (Gulbenkian, Sabanci, Atlantic Philanthropies, ONCE, Banca di Monte di Lucca and the Fondation de France). Others are currently in the process of engaging with the Consortium.

By working in partnership, our shared overall aim in the Consortium is to breathe life and vigour into the application of the United Nations (UN) Convention in Europe, thus making a distinctive contribution on behalf of the European foundation sector. We aim to play a constructive, catalytic role so as to ensure that European governments, public authorities at all levels and other relevant stakeholders both commit to and support the ratification and active implementation of the Convention.

Put more concretely, the Consortium 's objectives are to :

- Encourage the effective application of the Convention both at EU level and in all Member States of the EU, by **promoting enhanced cooperation** between all interested parties (legal, human rights, medical, research, public authorities and civil society) with the active involvement of disabled persons themselves;

- Contribute towards **building up the expertise required** to ensure the transposition of the Convention and its effective application in Europe; and
- **Support Technical monitoring** of the operational progress in implementing the terms of the Convention so as to identify additional ways in which the foundation sector may contribute, both through its advocacy work and by supporting joint transnational ventures which point to good practices and inspire others to action.

Why is the UN Convention so important?

The UN Convention is the first human rights treaty of the XXIst century which cleverly combines civil and political rights as well as economic, social and cultural rights under an overarching theory of non-discrimination. It is without doubt the single most exciting development to take place in the disability field for many decades. It is a significant landmark treaty, which will accelerate the momentum of the world-wide process of law reform in the field of disability.

The UN estimates that there are 50 million persons in the world who are disabled, classifying them as “the world’s largest minority”. Within the EU disability affects at least 50 million persons. The potential benefits of effective implementation of the Convention are therefore enormous.

As we know, in the past, human rights has not been the framework for considering disability. Rather it has been pursued by a mixture of social policies, charity and paternalism. Indeed, the general social policy purpose has been to maintain people rather than to forge pathways for them into the mainstream.

With the Convention, the question of disability has moved to the core of the UN human rights agenda. The UN Convention on the Rights of Persons (CROD) with Disabilities has a number of strengths which have a positive influence on the development of international standards in equality and human rights law. It is a step forward in human rights standard setting generally, not just within the area of disability rights. The strengths of the Convention include a number of important features that I would like to highlight today.

It represents a breakthrough which should encourage equality advocates in all fields. It is the first international legally binding human rights treaty that contains key principles developed since the late 1980s. It refers (and I quote) to “the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms”. This is a paradigm affirmed by the 1993 Vienna World Conference on Human Rights but now we see this wording incorporated in this Convention.

The Convention has as its purpose not just the elimination of discrimination (of persons with disability) but the promotion of equality: It not only mentions equality

explicitly (unlike the previous generation of conventions) but expresses a modern, progressive understanding of equality. It goes further than a) equality before the law b) equal treatment and c) equal opportunity and – consonant with best modern practice (as developed especially in the EU) promotes d) equality as participation. It contains language which suggests a fully developed legal concept of substantive equality, e.g. and I quote again “**full and effective participation in society on an equal basis with others**”, “**participation as equal members of society**”, “**full and effective participation and inclusion in society**”. This is a remarkable step forward as previous UN Conventions talked only about a right to non-discrimination and not about equality.

The Convention emphasizes the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development. This principle can be extended to cover, by analogy, the rights of other vulnerable groups. While this sounds familiar to the social policy expert, this principle has not been explicit in human rights law.

And it features a modern conception of human agency and the related issue of legal capacity. It stresses individual autonomy and independence, including the freedom of the persons covered by the Convention to make their own choices .I quote : “Considering that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them”. This is a welcome departure from the traditional construction of the “victim” in earlier generation human rights law.

Furthermore the Convention explicitly refers to the importance of multiple discrimination. This is an inspiration for the current efforts of anti-discrimination lawyers particularly in the EU to codify prohibitions of multiple discrimination.

It makes a helpful link between the enjoyment of human rights and the eradication of poverty, and in this regard recognizes the critical need to address the negative impact of poverty on persons with disabilities and by analogy on other vulnerable groups. Again, while this nexus may sound banal to policy makers, it is now part of international human rights law. This can be an important point to highlight especially in this European Year for action against poverty and social exclusion during these tough times triggered by the recession.

The Convention provides a strong concept of “reasonable accommodation”. Equality lawyers should try and are currently trying to extend this legal concept to discrimination on other grounds, such as age, religion, etc. A generalized definition of “reasonable accommodation” taken from the Convention was for example included in the 2008 Declaration of Principles on Equality facilitated by The Equal Rights Trust London) and distributed to governments worldwide.

It also explicitly addresses the difficult issue of the personal scope of human rights Conventions i.e. the question as to who is bound by the Convention norms. The state (and again I quote) has the obligation “to take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise”. Thus, discrimination by non-state actors is also covered. While EC law on discrimination has always covered private parties (as it derives from employment law), the question is not so straightforward in human rights law.

There are further positive features of the Convention, including the way it approaches the link between humanitarian and human rights law; legal capacity; and then of central importance the requirement to “closely consult with and actively involve persons with disabilities”. NOTHING ABOUT US, WITHOUT US. The duty therefore of the EU and public authorities is to ensure the essential involvement of disabled persons in shaping and implementing practices affecting their interests. This too is basic to the approach of the Consortium and why in particular we engage in all our work actively with the European Disability Forum which represents disability organisations throughout the EU.

The Consortium’s activities

I would like to update you briefly on a number of the Consortium’s activities:

➤ **Public presentation of the European Consortium of Foundations on Human Rights and Disability;**

The Consortium was launched at the European Parliament last 1 April 2009. The launch event was attended by Members of the European Parliament, representatives of the European Commission, members of the Commission’s High Level Group on Disability (appointed by the EU Member States), representatives of civil society organisations (NGOs) working to defend the rights of people with disabilities, and representatives of the European Foundation Centre (EFC) as well as the foundations which had joined together to create the Consortium.

➤ **Study on “Challenges and good practices of the UN Convention on the Rights of Persons with Disabilities at the European Union”;**

The Consortium is currently carrying out for the European Commission a study on the challenges and best practices of implementation of the UN Convention in the European Union. The findings of the study will inform policy-making at EU level and identify where legislative changes are needed both at EU level and in the Member States.

It is directed by Professors Gerard Quinn (National University of Ireland) and Lisa Waddington (Maastricht University) . The research team is scanning the most relevant EU and member state legislation and identifying those laws and policies which need to

be reformed to comply with the requirements set out by the UN Convention. A collection of best practices on the implementation of this groundbreaking international treaty will be also published, along with a mapping of all EU governments' units involved in the UN Convention's implementation. We are in the process of finalizing this report which will be presented shortly to the Commission with a view to its wide public dissemination in 2010.

➤ **Conference on the legal capacity of persons with disabilities (Article 12 UN Convention);**

Another stream of the Consortium 's work has involved the organization of seminars to discuss with and provide policy-makers and legislators solutions for the less clear or more contentious issues. In June 2009 we organized in Brussels, jointly with the European Foundation Centre, a seminar on Article 12 of the UN Convention, which deals with the legal capacity of persons with disabilities, one of the UN Convention 's grey areas and, possibly, one of the elements that will be more difficult to put in practice. The approaches to this issue vary enormously from country to country. Moreover, the legal capacity of persons with disabilities will have an impact on a number of other associated rights, like right to have adapted information, right to decide about medical treatments, right to vote, etc.

This seminar shed some light on the problems related to this challenge. It was not a seminar open to the general public but rather a technical discussion between experienced experts in the field who exchanged views on the issue and pointed out where the main obstacles could be found and how to overcome them.

➤ **Seminar on Setting Up Of National Implementing Bodies**

In October 2009, jointly with the European Disability Forum (EDF), we organized a seminar on another important topic, the creation of national implementing bodies. These are and will be the keys to make sure that the Convention is successfully applied at Member State level. Again we brought together representatives from the European Commission, some national governments and some leading world experts to exchange ideas and best practices on the way signatory countries deal with this requirement and how they plan to best meet the demands of persons with disabilities and their representative organizations.

The challenge posed by the Convention is to embed a new dynamic of reform in the Member States and their regional and local processes of governance. Article 33 is the lynch-pin which can pave the way to a new institutional architecture. Three points are vital here:

- Governments must designate one or more focal points, avoiding siloh thinking of different departments and focussing responsibility;
- Governments must designate a Coordination Mechanism; and

- they must also create an independent monitoring mechanism to “protect, promote and monitor the application of the Convention”.

The importance of developing a comprehensive and integrated approach to the Convention underlies these three features.

➤ **Publication of recommendations on the implementation of the UN Convention based on foundations’ experiences;**

Foundations can and do play a key role in the UN implementation process. As inclusive organisations by nature, foundations often have a relevant expertise and experience in including persons with disabilities in their work and in their activities. This expertise can be exploited as an example of best practice in the implementation of the UN Convention on the Rights of Persons with Disabilities. We plan to elaborate a foundations’ best practices compendium for the attention of other foundations and other citizens’ organisations active in the disability and human rights field, as well as for public administrations.

➤ **Cooperation agreements with legal operators (lawyers, notaries, judges and ombudsmen) to mainstream the UN Convention in their work;**

Professionals working in the legal area play a crucial role in the practical implementation of any international treaty on equality and anti-discrimination. However, they are too often left aside in the deliberations on and preparations for its practical implementation.

To avoid such a situation in respect of this UN Convention , the Consortium has already signed co-operation agreements with the European Associations of notaries, magistrates and public prosecutors, and is working on further agreements with lawyers and national ombudsmen. A common feature of these agreements is the organization of training modules and dissemination activities. We are also in the process of developing a course on the Convention with the Academy of European Law (ERA), which trains hundreds of lawyers each year.

The EU and the UN Convention

The Convention entered into force on 3 May 2008. Significantly, the ratification by the EU itself as a signatory was concluded only a couple of weeks ago (26 November 2009). This is unprecedented, as it is the first United Nations Human Rights Convention which the Commission has ratified on behalf of the EU. The Commission's present Action Plan on Disability (2008-2009) lists the implementation of the Convention as one of its main priorities. The Convention can also be expected to play a prominent role in

the thinking of the Commission in defining its future strategy with respect to its interdepartmental policies, and legislative agenda in the disability field. This implies that it should have a clear place in the new EU 2020 programme proposals which President Barroso and his new team will prepare to replace the former Lisbon Agenda.

Of especial importance will be the definition of the next phase of EU Structural Policies and Funds which will operate in the period from 2014 to 2019/20. Here the European Social Fund (ESF), the European Regional Development Fund (ERDF) and the Agricultural Guidance Fund (FEOGA with its rural development focus) will be adapted to meet the priorities which will be defined in the new overall EU strategy text. It is clearly vital that the new Regulations which will govern these policies in future should explicitly refer to the terms of the Convention and provide a wide range of support at local levels to improve as a matter of right the living and working conditions of disabled persons. This priority must find its place in the overall EU effort to combat joblessness , poverty and social exclusion whilst also promoting innovation, research and development , and lifelong learning to create the conditions for a successful European integration process visible to and appreciated by the citizens of the EU.

Conclusion

Foundations have several important and distinctive characteristics : independence of status and capacity to do what governments often cannot or dare not do. They can and often do take risks. They frequently back initiatives in a long term perspective unlike governments so often trapped into short –term considerations. Also foundations have their own resources, sometimes very significant, which they can use to give complementary and added value to the initiatives of public authorities. For this reason, we are delighted that the Gulbenkian Foundation, with its huge reputation internationally as well as in Portugal, is an active partner in the European Consortium. Working with all other partners, we are determined together to demonstrate the importance to society as a whole of achieving the effective implementation of the Convention at the grass -root level and to create the conditions for sustainable policies and practices which respect the rights of disabled persons. I look forward to learning about your various initiatives in Portugal to transform the Convention into a reality here in Portugal.

Thank you for your attention and for this opportunity to collaborate with the Gulbenkian Foundation.