The UN Human Rights of Persons with Disabilities Treaty: A Blueprint for Disability Law & Policy Research and Reform

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1. Introduction.

2. The Treaty.

- *The Treaty as a Mirror to Society.*
- *The Core Values of the Treaty.*
- *A Non-Discrimination Treaty Mixed with Substantive Rights.*
- *The Treaty Combines 'Obligations of Result' with' Obligations of Conduct'.*
- *The General Obligations of States.*
- *The Rights.*
- *Enforcement.*

3. The Treaty as a Blueprint for Reform & Research.

1. Introduction.

I thank the NDA and especially Mary Van Lieshout and Frances Hannon for the high honour of addressing this conference.

I want to share some reflections on the new UN treaty on the rights of persons with disabilities. The treaty took over four years to draft and should come into force sometime next year.

There are over 800 million persons with disabilities in the world – 80% of whom live in developing countries. That would make at least 100 million persons with disabilities in China and India respectively.

I am conscious that that I share my reflections a poor substitute for Ambassador Don MacKay. Ambassador Don MacKay was the key person in making this treaty a reality. He – and the country he represents before the UN, New Zealand – deserve the highest praise for his wise helmsmanship of the process.

Quite a lot of Irish people also played their part. Arthur O'Reilly must be considered one of the fathers of the treaty. Our Department of Foreign Affairs participated actively and very constructively. Donal McAnaney of Rehab kept the process in the public eye and made sure that ordinary voices could be heard. The NDA held an important seminar in June of this year on the issue of capacity and the convention. Our Human Rights Commission took a very active part in the negotiations and continues to coordinate the input of European human rights commissions on the topic. And countless Irish NGOs made their presence felt across a wide range of issues.

Back to lawyers. I recall the words of a French aristocrat who once said:

> Lawyers are like weeds that grow in gardens cultivated by the hands of others. And once they take root they extinguish all other living vegetation.

But I trust you believe me when I say that I am here for another reason.

- That reason has everything to do with the connection that should exist between law and justice.
- It has everything to do with the potentiality of the UN treaty as a driver of disability law reform in Ireland and indeed throughout the world.
- And it has everything to do with the kind of research needed to make sure that the 'paper rules' of the treaty become the 'real rules' according to which public policy is re-framed. As we all know too well, it is one thing to ratify an international treaty – it is quite another to anchor it in the domestic legal and political order as a motor force for change.

The disability treaty will be the first human rights treaty adopted in the 21st century. It was agreed in August and will be adopted and open for signature/ratification by the UN General Assembly on December 5 in New York. A new UN Committee on the Human Rights of Persons with Disabilities will be established to assess periodic State reports on the progress they have made under the treaty.

The treaty covers a very broad range of areas such as employment, accessibility, education, freedom from exploitation, independent living and a right to be recognised as a person before the law. All of these fields have undergone major change in Ireland in the past decade. All of them will be touched by the treaty. And all of them can benefit from the fresh perspective the treaty offers.

Just as the Report of the Commission on the Status of Persons with Disabilities became the main inspiration for Irish law reform in the last decade this treaty promises to do much the same into the future – and not just for Ireland.

The treaty is accompanied by an optional Protocol – which is just that – optional. This Optional Protocol enables States to recognise the competence of the new UN Committee on the Rights of Persons with disabilities to lodge complaints and have them adjudicated upon. So when Ireland ratifies the treaty it will also have the option

to ratify the Optional Protocol allowing persons to bring complaints before the new UN Committee. I would encourage it to do so.

Assessing periodic State Reports every few years is one thing. The process can be quite abstract and devoid of the human element. Allowing the individual's perspective to emerge through a complaints procedure enables the raw edge of human experience to be expressed. It is mainly through such cases that bodies such as treaty monitoring bodies can develop and deepen the jurisprudence or caselaw. And the clarification of State obligations that results can only be of benefit to States as well as to the individuals affected. That, at least is my own view and that is why I would urge Ireland to ratify both the treaty and the Optional Protocol.

The disability treaty is expected to become one of the most widely ratified treaties – in part because it carries no baggage from the Cold War.

It should underpin the reform processes underway in many countries as diverse as Ireland and China – and give them more coherent direction.

It should inspire reform processes to take place in countries where none currently exists.

It gives a language and a philosophical frame of reference to those who feel aggrieved but who will now acquire a language to engage with power.

And the development aid provisions should have a dramatic effect throughout the world – not least in the way we deliver Irish aid in Africa.

2. The Treaty.

First things first. You may ask, why a treaty? Indeed, you may ask, so what? Even if a treaty is adopted there is no guarantee – no mechanism – to ensure strict domestic compliance which is where the rubber hits the road.

Treaty as a Mirror to Society.

I think a disability treaty was needed for many reasons – but one stands out for me. It has nothing to do with law – and everything to do with the war of ideas.

Persons with disabilities were legally and politically 'disappeared' in most countries of the world (this is my phrase and it is an exaggeration). Their absence from the mainstream was explained as somehow 'natural'. William Blackstone, a famous English legal historian writing several centuries ago once said "upon marriage women suffer civil death". What he meant was that their 'legal personhood' – their recognition as a full human being in the eyes of the law – was merged with that of their husband's. They became in effect, property. And the history of law reform ever since has been to return to women the full indicia of the legal personhood.

Somewhat similarly, persons with disabilities suffered a form of "civil death". It is remarkable how in many different cultures throughout the world persons with disabilities were effectively treated as lesser human beings. It is as if the rationality of our values (valuing each human being equally) pointed in one direction and our culture pulled in the other. And the contradiction was not even experienced or acknowledged a contradiction.

So, for me, the treaty basically places a mirror before society. It makes us face up to our own values – to our so-called 'legacy values' of dignity, autonomy equality and social solidarity. It forces us to acknowledge the large gap that still exists between the 'myth system' of our values and the 'operations system' of how these values are in fact dishonoured in daily practice.

The treaty, then, is a force for rationality as well as a vehicle for carrying these values squarely to the heart of the disability field. It contains an ethic of justification that requires States to respond.

As with all mirrors we can refuse to look at it, or we can look at it but ignore its reflection or we can take notice of our reflection and commit to a process of change. The treaty is a trigger for this worldwide process of change which is likely to accelerate in the next five years.

The Core Values of the Treaty.

Why is this treaty important in the Irish policy process? What does it add?

If you want to unpack the heart of the Treaty – and to glean its added value in the domestic disability debate - look to Article 3. In that Article the values or principles that animate the treaty are said to be: dignity, individual autonomy (including the right to make one's own choices), non-discrimination, full and active participation and inclusion, respect for difference, equality of opportunity, accessibility, equality between men and women and respect for the evolving capacities of children with disabilities.

These values are important, for in the words of the Chair of the drafting committee, 'they embody the paradigm shift' away from welfare and towards equal rights. Indeed, they give clearer expression to the operating principles of the Commission on the Status of Persons with Disabilities. The other, more established core human rights treaties proved unavailing in the disability context. They could have been put to good use in the disability context but suffered from the same 'invisibility' of persons with disabilities.

A Non-Discrimination Treaty Focused on Substantive Rights.

As to the kind of treaty that the disability treaty could have become, the drafters were presented with a choice at the outset.

> The treaty could have become a substantive treaty containing stand-alone substantive rights like the Rights of the Child Convention. This would have been quite robust. It was my preferred format.
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> Or, to go to the other extreme, it could have been just a simple non-discrimination convention containing a bald proscription against unfair treatment. Indeed, there were one or two proposals to this effect. That would not have been of much use because it would simply have focus on the need to ensure equal treatment in the abstract without reference to any particular policy area and without reference to go the extra mile to provide material

support to enable persons with disabilities to exercise their rights in reality and not merely on paper.

Or, it could have been a mix of a non-discrimination treaty that attached to a broad swath of rights such as life, liberty, education, etc. This was in fact the approach adopted. So the treaty blends together a large continuum of substantive rights like the right to education and then animates them from the perspective of the equal effective enjoyment of these rights using the non-discrimination tool.

The goal, in the language of Ambassador McKay, was not to create new rights – but to ensure through the use of the non-discrimination principle that all existing rights were made equally effective for persons with disabilities. So the arguments for particular articles focused on the existing continuum or rights under international law and to identify what extra was needed in order to give equal effect to these rights an to tailor them in the context of disability.

So non-discrimination is the animating principle and it interacts with the various substantive rights – some of which are more substantive than others.

While on the subject of non-discrimination, it has to be recalled that comparative law throughout the world adds an obligation of 'reasonable accommodation' in the context of disability. Failure to achieve it is automatically deemed to be discrimination under most comparative law. For purely technical drafting reasons the notion of 'reasonable accommodation' was separated from the notion of non-discrimination in the EU Framework Employment Directive of 2000. This led the EU Presidency to argue in a crucial session in 2004 that while failure to achieve 'reasonable accommodation' under the treaty might be regrettable it did not amount to discrimination. Thankfully the Presidency did not pursue this line of reasoning and failure to achieve 'reasonable accommodation' is now deemed by Article 2 to be a form of discrimination.

The Treaty Combines Obligations of Result with Obligations of Conduct.

One of the interesting things about the treaty is that is combines both civil and political rights with economic, social and cultural rights. Indeed, this may have been the main reason why the EU Presidency hesitated to allow failure to achieve 'reasonable accommodation' to be deemed a form of discrimination.

Let me explain. Because economic, social and cultural rights are presumed to be more resource-intensive (which is actually not always the case), there tends to be a bias against allowing them any form of enforceability – much less judicial enforceability – in many countries. International law tends to draw a distinction between 'obligations of result' which must be immediately achieved and 'obligations of conduct' which ware more programmatic in nature. Non-discrimination is taken to create an 'obligation of result' which generally attracts judicial enforcement. Provided States can show good faith efforts to progressively achieve programmatic obligations or obligations of conduct then they have discharged their obligations under the relevant treaty.

The EU Presidency may well have feared that the non-discrimination principle with 'reasonable accommodation' attached could have become a Trojan horse for the judicial enforceability of economic, social and cultural rights. This was because the non-discrimination principle in the disability treaty attaches to all the rights of the treaty which includes classic rights like liberty but also to resource-intensive rights like education. Whatever the motivation of the Presidency, the non-discrimination principle is now clearly engaged if 'reasonable accommodation' is not provided on a wide range of rights.

Article 4.2 is to the effect that with respect to economic, social and cultural rights, the main obligation on a State is to progressively achieve the same. In short, the treaty creates 'obligations of conduct' with respect to programmatic rights and 'obligations of immediate result' with respect to civil and political rights. Thus the 'danger' of attaching 'reasonable accommodation' was 'solved'.

This is an important point to dwell on. Disability is interesting. It is obviously not enough in many instances to enact laws banning discrimination. To make freedom and choice a reality it is often necessary to provide some sort of material underpinning

to individual choice. People need laws to be allowed to go through doors – they may need support to actually make it through.

Disability makes obvious what is the case for most people and groups – we rely on each other – on social solidarity - to ensure that freedom is a reality and not just a figment of liberal imagination.

So, at home here in Ireland, it was necessary to move beyond our excellent corpus of discrimination legislation to place these programmes across a broad range of fronts on a legislative basis which is essentially what the Disability Act of 2005 does. And, at the international level, it was also obviously necessary to include economic, social and cultural rights into the disability treaty – otherwise it would just provide mere ‘paper rules’.

Here we bump up against a deep prejudice in most legal systems against economic, social and cultural rights. That is why the formula used in Article 4.2. was adopted. Your natural reaction may well be “well, if resources are vital and if this treaty cannot drive the resource allocation process then of what use is it in the disability context.” This is a fair question. Let me answer it like this.

There are two popular misconceptions at polar ends of a continuum on this point. The notion of ‘progressive achievement’ is popularly misunderstood to mean that the State is completely free to make whatever allocational decisions it wants – to postpone, delay, prevaricate, temporise or simply not make ‘progress’ as it sees fit and responding only to whatever interest groups have the loudest voice and to the permanent exigency of maintaining the wealth-creating capacity of the economy. This view of ‘progressive achievement’ as a *carte blanche* to Governments is wrong.

The other popular misconception is that the State is tied, bound, directed even micro-managed as to what it spends, when and how. No matter how one might wish this to be so, it is not so under international law.

The notion of ‘progressive achievement’ under international law mediates between the two polar extremes. It genuflects before the exigencies of governing which

involves choice and often allocative choice. It honours the ‘separation of powers’ which insulates courts especially against having to micro-manage budgets. However, and this is crucial generally and also in the disability context, it does not surrender all choice to the State. General Comment 3 under the Covenant on Economic, Social and Cultural Rights states for example,

> Nevertheless, the fact that realization over time, or in other words progressively, is foreseen under the Covenant should not be misinterpreted as depriving the obligation of all meaningful content. It is on the one hand a necessary flexibility device, reflecting the realities of the real world and the difficulties involved for any country in ensuring full realization of economic, social and cultural rights. On the other hand, the phrase must be read in the light of the overall objective, indeed the raison d'être, of the Covenant which is to establish clear obligations for States parties in respect of the full realization of the rights in question. It thus imposes an obligation to move as expeditiously and effectively as possible towards that goal.
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> Moreover, any deliberately retrogressive measures in that regard would require the most careful consideration and would need to be fully justified by reference to the totality of the rights provided for in the Covenant and in the context of the full use of the maximum available resources.

Why do I stress this? I do so because many of the obligations in the disability treaty are ‘obligations of conduct’. That does not rob the treaty of autonomous meaning in the context of disability – it does not surrender the notion of ‘progressive achievement’ to the absolute discretion of the State.

Let me illustrate. A Collective Complaints mechanism does in fact exist under the Revised European Social Charter of the Council of Europe. A complaint was brought about three years ago alleging poor rates of integration of autistic children into education systems in France. The Committee decided against France and stated:

> When the achievement of one of the rights is especially complex and particularly expensive to resolve, a State Party must take measures that allows it to achieve the objectives of the Charter within a reasonable time, with measurable progress, and to the extent consistent with the maximum use of available resources. States Parties must be particularly mindful of the impact their choices will have for groups with heightened vulnerabilities as well as for other persons affected including their families on whom falls the heaviest burden in the event of institutional shortcomings.

So do not rush to the conclusion that the programmatic language of the treaty robs it of all normative bite. That will very much depend on the interpretative approach adopted by the new Committee. And as the above shows, it is certainly possible to marry a wide margin of appreciation for the State with a sense of the centrality of the rights in question.

Why am I saying this? I say it first of all to allay your initial scepticism about the value of the treaty – which is entirely natural. And secondly, among other things, the NDA has the onerous responsibility of monitoring the implementation of the various programmatic provisions of the Disability Act. I think much can be learned from international law about how to assess whether sufficient progress has in fact been made. In this regard the concept of 'progressive achievement' can be better reflected in domestic law and policy taking a cue from international law. A lot of borrowings both ways can take place.

General Obligations.

The treaty contains a lot of very specific obligations to be found scattered in the various rights covered. But it also contains an Article dealing with the general obligations of States (Article 4). Among other things this Article requires the adoption of fresh legislation where needed and the repeal of inconsistent legislation. This points strongly towards on ongoing and dynamic process of law reform.

It effectively calls for the mainstreaming of disability into all policies and programmes. It calls for 'universal design' including in fields such as information technology which is quite crucial. It calls for the training of all professional staff to include knowledge of and respect for the rights set forth in the treaty which is especially important across all service delivery organisations. It calls for active consultation with persons with disabilities in framing laws and policies that affect them.

Effectively, Article 4 seeks to place the treaty at the heart of domestic disability policy. It is for that reason that I said at the outset that it ought to become the new

blueprint for reform in Ireland – a worthy successor to the Report of the Commission on the Status of Persons with Disabilities.

The Report of the Commission was extremely influential overseas. Yet it was our Report and our blueprint. The treaty sets down an international blueprint. The international dimension to the treaty is set to become very significant.

For example, for some years now a few countries have made efforts to proof their development aid programmes from a disability perspective. This makes eminent sense. Building inaccessible schools in Africa through development aid simply cements a cycle of exclusion into place. Article 32 now deals explicitly with the issue. It effectively requires that international development programmes are inclusive of, and accessible to, persons with disabilities. Its hard to see how this can be done without proactively proofing those programmes from a disability perspective – as is currently done by the German Foreign Ministry as well as USAID. This is something the World Bank is becoming increasingly interested in. In passing, let me say that I am very glad that the recent excellent Department of White Paper on Development Aid explicitly deals with the disability perspective to development aid. The next step is to put in place an adequate and effective proofing mechanism. Research is clearly needed to do a good job on this.

There are other international dimensions to the treaty that are also important including the obligation to facilitate cooperation in research, sharing assistive technologies. Permit me to conjecture that international research will become crucial. Its one thing for an international body to cast a negative judgement on a country. Its another thing altogether to work co-operatively together to identify common problems and share practical solutions that can work. That search for solutions will more and more take an international and comparative shape

The Rights.

The treaty is very long and contains 50 Articles – most of which contain a wide variety of substantive rights. I won't exhaust you by going through them all. There are many ways of rendering the rights. One way I like to think of them is with reference to the core values contained in Article 3.

The *dignity* rights cover, for example, the right to life, freedom from torture, freedom from exploitation, violence and abuse and protections for the integrity of the person. These latter rights are especially important in institutional or residential contexts and perhaps even in the home.

The *autonomy* rights cover, for example, the right to recognition as a person, the right to live independently, the right to habilitation and rehabilitation as an aid to independence, privacy, a right to home and family.

The treaty innovates in carrying these autonomy rights a step further by protecting rights to participate in all aspects of society. Such rights include a right to accessibility, a right to participate in political and public life, a right to participate in cultural life and a right of access to justice.

A variety of important liberty rights are also protected in including liberty of the person, liberty of movement and nationality and right to personal mobility.

The *Equality* rights cover for example, the right to equality and non-discrimination.

The *solidarity* rights cover, for example, the right to education, the right to health, a right to an adequate standard of living and a right to work and employment.

Personally, I find the right to independent living to be tremendously important in light of the worldwide trend in favour of deinstitutionalisation and toward living in the community. Indeed, deinstitutionalisation is probably the single most urgent challenge worldwide at the moment – with all that this implies for human dignity, exploitation and violence behind closed doors.

I also find the family rights to be extremely important. One suspects that persons with disabilities, for example, have found it hard to adopt children in many countries on the basis of their disability. If so, this will no longer be possible to be consistent with the treaty.

The access and participation rights are also very important. The participation rights cover participation in political and public life (Article 29). It covers issues like accessible voting and the provision of political information (such as policy documents and manifestos) in formats that are accessible to all. Public life is an elastic term that can for example include jury duty – especially in combination with Article 13 dealing with access to justice. It is my understanding, for example, that deaf people are still excluded from jury service in this country. This is an excellent example of a law and practice that must be changed if the treaty is to be successfully adhered to. It can easily be done and should have been done years ago.

The provisions on the built environment are as one might expect. What is really interesting about the treaty is the provisions it contains on requiring the Information Society to become accessible to persons with disabilities (Article 13). Here the business case for change seems to converge nicely with the moral call for change. The treaty clearly requires countries to make their Information Society regime open to persons with disabilities. Permit me to suggest that these provisions will prove crucial as the Information age really takes off. I know the NDA is already doing excellent work in this regard which deserves a wider international audience.

And the provisions dealing with recognition in law as a person (Article 12) are profound in the extreme. Most countries around the world over-conflate incapacity. That is, the law too quickly moves from even a minor factual incapacity to assume total and complete legal incapacity. Once you are deemed legally incapacitated, persons no longer have any control over their personal destiny. There is a worldwide trend away from this Victorian view of the human person – a trend that was pioneered by the Law Commission of England and Wales and which is being forcefully advanced by our own Law Reform Commission to its great credit. Article 12 reflects this trend. It reflects especially the notion that persons should be supported in their decisions and in their decision-making capacity if needed – but not substituted. It reflects the principle of proportionality – a principle conspicuous by its absence in the past – in any interventions in the field.

The drafting of this Article proved very controversial because of contending views about capacity and its limits. A footnote was added by China and others to the effect

that, for China, the term ‘legal capacity’ means ‘capacity for rights’ rather than a ‘capacity to exercise rights’. This is very unusual. Usually, a reservation would cover this sort of terrain. My information as of yesterday is that China is poised to withdraw the footnote although one or two other countries might insist. If so, this move by China is to be greatly welcomed.

Enforcement.

As indicated earlier the new Committee on the Rights of Persons with Disabilities will assess periodic State Reports on progress achieved and obstacles encountered. It is common practice for the other UN treaty bodies to hold a dialogue with the State Party concerned. The existing treaty bodies then formulate conclusions or concluding observations regarding the State Party indicated where progress has been achieved and where setbacks need to be rectified. This Committee is likely to follow suit. Indeed, it is given explicit power to formulate General Comments which clarify State obligations from time to time. If past experience is anything to go by, there will be ample space for civil society to interact with the new Committee.

What is especially interesting about the treaty is the detailed treatment of domestic implementation and monitoring. Article 34 requires – where not already done – a focal point within Governments on the implementation of the treaty. This should ensure joined-up implementation. Recall, this was a core recommendation of the Commission on the Status of Persons with disabilities in 1996. We already have that in the shape of a junior Minister for disability who helps mould the agenda and keeps all arms of State working toward the same end.

Article 31 deals explicitly with statistics and data collection. Logically, such data is needed on which to make rational policy choices. And Article 31 was inserted for exactly that reason. Interestingly an earlier version of it was also opposed by the EU Presidency but the opposition fell away as it became clear that safeguards covering privacy would be insisted upon.

But Article 34 goes on to call on States Parties to “maintain, strengthen, designate or establish…a framework including one or more independent mechanisms…to promote, protect and monitor implementation of the treaty”. This body – or bodies –

should take into account the principles (Paris Principles of 1993) relation to the establishment and functioning of national institutions for the protection and promotion of human rights. These tasks – **promotion, protection and monitoring** – are to be left to agencies that are genuinely independent of the State.

Ireland has in fact a rich tapestry of institutions dedicated to the identification and pursuit of the public interest in the broad field. These bodies include the NDA itself, the Human Rights Commission, the Equality Authority, the Law Reform Commission and more recently the Mental Health Commission. Conversations have yet to take place about which institution should do which mix of promotion, protection and monitoring and I certainly do not want to prejudice the outcome. The time for that will be when Ireland signs and ratifies the treaty.

3. The Treaty as a Blueprint for Reform and Research.

So the treaty will be adopted in December and then opened for ratification. Then what? Article 45 is to the effect that the Treaty shall enter into force upon the 20th ratification. Hopefully, that will happen by Summer 2007. Elections will then have to take place for the new UN Committee to interpret the Treaty.

It would be a mistake to think that the treaty is a panacea. It is not. However, it is more than a mere piece of paper. It has a higher status than, for example, the Council of Europe's ten year action plan. It enshrines the ethic of justification. It places a clear onus on States to justify their policies – their progress or lack of progress – in advancing the rights of their disabled citizens.

It would be a pity if the treaty were simply looked upon negatively as a side constraint on State policy. Put positively, it provides a normative steer, it provides a clear reform blueprint, for States. It should be placed at the heart of State law and policy.

For the first time, it enables a rational dialogue to take place at international level on precisely is meant by a rights-based approach to disability and topic by topic. This dialectic can only be to the advantage of Governments eager to know the boundaries of their obligations and to disabled citizens who deserve to know how their rights will be enforced.

The treaty should, in short, play the same role that the Report of the Commission on the Status of Persons with Disabilities played with the clear advantage that it has been authorised by the international community and it will be husbanded and grown internationally.

It follows in my view that the excellent research efforts of many public institutions in this country – including the NDA, the Human Rights Commission, the Equality Authority and the Law Reform Commission will be vital in enabling our Government to successfully implement the convention – to become a leader and not just a follower on the international stage.

It also follows in my view that this research needs to become much more international. That is to say, while our primary responsibility is to our citizens, we should be even more open to learn from others and to contribute our know-what and know-how to others. International research is perhaps the best way to do this. It shows not merely what ought to be – it also shows what can be by looking at innovative solutions adopted elsewhere. The transfer of this know-how from country to country will play a very large role in enabling the treaty to become a success.

It should impact on how Ireland inc. delivers its development aid so that Ireland can play its part to elevate the status of persons with disabilities throughout the world.

Maybe the treaty reminds us that the daily quest for justice here is intimately tied to the quest for justice with our nearest neighbours in the UK and much further afield. In this spirit I leave you with a quote which certainly animates much of my work:

> "…we can perhaps remember –even if only for a time – that those who live with us are our brothers and sisters; that they share with us the same short moment of life; that they seek – as we do – nothing but the chance to live their lives in purpose and happiness, winning what satisfaction and fulfilment they can".

I did not write these lines – but I wish I had. They were not even written by a European. In fact they were written by Senator Edward Kennedy in 1968 to eulogise his slain brother - Robert Kennedy. Though written against the backdrop of a personal tragedy, they nonetheless contain the seeds of hope. For they pronounce a certain moral vision of the political community – one that happens to nicely express the essential moral and political mission of the treaty. Human diversity constitutes the very bedrock of our unity, a celebration of what it means to be a human being and not, as too often in the past, an occasion for exclusion and discrimination – whether overt or covert.

It is in this spirit that I commend the treaty to you.