8<sup>th</sup> International Summer School on Disability Law

Centre for Disability Law & Policy National University of Ireland (Galway)

# **Bringing Rights Home**

### **Civil Society Impacting Change**

### Making the Most of The New Politics of Disability created by the UN CRPD

Director: Professor Gerard Quinn





20-24 June 2016 Venue: Institute for Lifecourse and Society, National University of Ireland, Galway, Republic of Ireland. <u>www.nuigalway.ie/cdlp/summer\_school/about.html</u> <u>Disabilitysummerscho@nuigalway.ie</u> #DSS2016

### **Introduction to the 2016 Programme**

In recent years the Summer School has adopted a general theme. The overall theme of this year's Summer School is how civil society can, with the right knowledge, insights and skills, capitalise on the 'new politics of disability' opened up by the UN CRPD around the world in both developed and developing countries. This emphasis on effective advocacy will build on successive Summer Schools that have focused on various substantive rights and themes.

The 8<sup>th</sup> Summer School (June 2016) will examine highly innovative and creative advocacy from around the world - what has worked, what doesn't work, the surprise advances and the unexpected setbacks. It will learn from those at the front lines of change across a range of issues and with a highly impactful track record. It will learn from advocates in many different countries and especially from the developing world. It will afford the participants an opportunity to stand back and reflect on their own advocacy and other strategies as well as share their experiences with a very diverse group. It will look at how civil society can amplify its voice by working in partnership with National Human Rights Institutions and with the many disability law clinics emerging throughout the world in universities. It will give participants an opportunity to reflect on the overall environment and especially the relative closure of space for civil society in many places in the world and its implications for disability rights advocacy.

The proceedings will be highly interactive with plenty of break-out space to reflect in smaller groups, especially about effective advocacy strategies in different countries. The participants are encouraged to share their own experience as much as possible since much of the deep learning will come from these interactions. Much of the proceedings will be videoed and placed on the Centre's YouTube site.

The initial morning - with Senator Harkin and others - will also be live-streamed.

### Day 1: Monday 20 June Looking Back – Looking Forward

**Rationale:** This is a day to both look backwards and to set the stage for moving forwards.

We will take a moment to glance backwards to the enactment of one of the most famous and impactful pieces of legislation in the world - the Americans with Disabilities Act (ADA) in 1990 and to learn from many of the actors who brought this Act into life. The amazing feat of advocacy that led to the ADA prodded advocacy around the world – and indeed provided a model not just for national advocacy in many other countries but also for advocacy for the drafting of the UN convention. The story behind the Act – why it was deemed necessary, the advocacy strategies pursued by civil society, the blueprints prepared, the attitude of Congress, etc., deserves to be told not only in its own right but because it is still capable of inspiring and informing similar advocacy around the world.

Following the ADA story we will look to disability advocacy challenges around the world and especially in developing countries. Although advocacy will be based in the same set of values as exemplified by the ADA and the UN CRPD it will necessarily take a different shape depending on local priorities, local political arrangements, culture and history.

As is customary, the opening day will also lay the foundations for looking forward. As is by now traditional, the day will also lay a foundation for understanding basic treaty law (how to interpret a treaty), the main features of the UN CRPD (the rights, the obligations and the monitoring and other mechanisms at international and domestic level). And ample space will be given for participant discussions on the climate for advocacy in their own countries and regions of the world.

#### Registration

**Welcome Message to Ireland:** President of Ireland, Michael D. Higgins

**Welcome to the University:** Professor Lokesh Joshi, Vice President for Research, NUI Galway

Looking Back: A Key Moment in World History – The Drafting of the ADA

**Keynote Address: Disability Rights – Looking Back: A US Invention brought about by American Civil Society** Senator Tom Harkin (D-Iowa rtd)

# **Response: How We Operationalised the ADA, the Challenges, Surprises and Successes**

John Wodatch, Former Director of the Disability Section of the Civil Rights Division in the US Department of Justice

### **Response: America Looking Outward: the US Taking Disability Rights Seriously in the World**

Judith E. Heumann, Special Advisor for International Disability Rights in the US Department of State

**Interactive discussion** with the speakers and the audience led by Martin Naughton, Co-founder of Áiseanna Tachaíochta, Adjunct Professor at the Centre for Disability Law and Policy, NUI Galway

#### **Tea and Coffee Break**

#### Looking Outward: Disability Rights as an American Invention and now a Global Challenge

Looking Forward: The New Disability Politics Made Possible by the UN CRPD – Disability as a Global Challenge Catalina Devandas, UN Special Rapporteur on the Rights of Persons with Disabilities

**Looking Beyond the Developed World: What Are the Advocacy Challenges in Developing Countries** Elizabeth Kamundia, Doctoral Candidate, University of Pretoria, South Africa

**The Advocacy Challenges and Process at European Level** Catherine Naughton, Executive Director, European Disability Forum

#### The Work of the Commonwealth & National Human Rights Institutions on Disability

Karen McKenzie, Head of Human Rights, Commonwealth Secretariat, UK

**Interactive discussion** with the speakers and the audience led by Martin Naughton

#### Lunch

**Treaty Law – the A, B, C's of Using and Interpreting a Treaty: Introduction to the Basics of Treaty Law** Mr James Kingston, Legal Advisor, Department of Foreign Affairs and Trade Ireland, and class exercise based on a proposed reservation to the UN CRPD

#### **Overview of the Rights & Obligations of the UN CRPD**

Dr Rosemary Kayess, University of New South Wales, Australia & former member of the Australian Government delegation

#### **Tea and Coffee Break**

#### Breakout sessions to reflect on the day's proceedings from the perspective of the participant's own countries and challenges

**Evening Social Activity:** A BBQ with Irish dancing and music is being organised for the participants at the end of the first day at the Radisson Blu

### Day 2: Tuesday 21 June Civil Society using the 'New Politics of Disability': Case Studies on Innovative Advocacy Throughout the World

**Rationale:** This is a day to reflect deeply on how civil society can – and does – take advantage of the 'new politics of disability' created by the UN CRPD to impact processes of domestic change. Over two days we will look at three sets of examples: (a) innovative civil society advocacy and how it impacts change, (b) civil society amplifying its voice through and with National Human Rights Institutions (NHRIs), and (c) civil society engaging with university-based research and law clinics throughout the world.

#### Chair: Diana Samarasan, Founding Executive Director, Disability Rights Fund

#### Report on breakout sessions from Day 1

Creative and Impactful Civil Society Advocacy

**Uganda: The Campaign for Accessibility Legislation** Apollo Mukasa, Ugandan National Action on Physical Disability

**Indonesia: The Campaign to Change Electoral Law** Yeni Rosa Damayanti, Head, Indonesian Mental Health Association

#### **Tea and Coffee Break**

Creative and Impactful Civil Society Advocacy (Cont.)

**Peru: Campaigning for Reform of the Peru Civil Code on Legal Capacity** Alberto Vasquéz, President, SODIS, Peru

#### Georgia: Campaigning for Community Living and Deinstitutionalisation

Giorgi Dzneledze, President, Coalition for Independent Living & Tamuna Nadiradze, Project Manager, Coalition for Independent Living

**Interactive discussion** with the speakers and the audience led by Diana Samarasan

#### Lunch

#### <u>Amplifying the Voice of Civil Society Through Other Change</u> <u>Agents – a Focus on the Relationship Between Civil Society</u> <u>and NHRIs</u>

#### Kenya: The Experience From Civil Society

Elizabeth Kamundia, Doctoral Candidate, University of Pretoria, South Africa

#### Germany: German Civil Society and the Institute

Valentin Aichele, Director of Disability, German Institute on Human Rights

Global Level: Draft Guidelines of the UN CRPD Committee on engagement with NHRIs – Ratcheting Up the Role and Function of NHRIs in the Context of Disability Around the World

Professor Gerard Quinn, Director of the Centre for Disability Law and Policy, NUI Galway

#### **Tea and Coffee Break**

**Interactive discussion** with the speakers and the audience led by Diana Samarasan on engagement with and through NHRIs – experiences of the participants

**Breakout sessions:** Small group reflections among the participants on activism generally as well as engagement with NHRIs

#### **OSF** Networking Event

Event for all OSF attendees to interact and network

### Day 3: 22 June Civil Society Working with and Through Others

**Rationale:** This day will build on the second day by looking at innovative examples of how civil society is working with and through other agents of change. The day will also look at the exponential expansion of new university-based research centres and disability rights clinics. These too help to expand capacity and potentially add to the repertoire of advocacy tools for civil society groups. It will examine the kinds of impactful relationships that can be forged and indeed the place of participatory models of research in the academic environment. To a certain extent the question is not so much how to use academic prowess to the best advantage of civil society but how to change academic processes themselves to put people with disabilities first.

To round out our examination of civil society as agents of change the day will also look at the turn towards more authoritarian restrictions governing the activities of civil society in many parts of the world. This is being done for reasons that are wholly disconnected from disability. But the closure of civic space has implications for all civil society groups including those in the disability space. To some extent the challenge is how to protect oneself in this confined space. At another level, the challenge is to think through how to have an impact regardless of the restrictive space. And indeed, a challenge is to think through the ethical implications of utilising whatever space is left in the field of disability and how to express solidarity with those who do not enjoy similar space.

Chair:

John Wodatch, Former Director of the Disability Section of the Civil Rights Division in the US Department of Justice

#### **Report on breakout sessions from Day 2**

<u>Civil Society Harnessing New University-based Research</u> <u>Centres & Disability Law Clinics</u>

# University-based Research Centres and their Relationship with Civil Society – My Experience

Professor Rannveig Traustadóttir, Centre for Disability Studies, University of Iceland and past president of the Nordic Network on Disability Research (NNDR)

The Embryonic Network of Disability Rights Clinics Around the World and their Relationship to Civil Society Groups in the International and Regional Treaty System Dr Eilionóir Flynn, Deputy Director, Centre for Disability Law and Policy, NUI Galway

#### **The Success of the Disability Law Clinic in Tbilisi** Giorgi Dzneledze & Tamuna Nadiradze, Georgia, Coalition for Independent Living

**Interactive discussion** with the speakers and the audience led by John Wodatch on engagement with and through universities & the experiences of the participants

#### **Tea and Coffee Break**

#### The Relative Closure of Civic Space in the World and its Implications for Disability Civil Society

Due to its sensitivity, this session is closed to the public and will not be filmed. The participants will learn about the relatively recent phenomenon of the closure of civil space in many countries across the world and reflect together on the implications that this has for their own advocacy efforts in the specific field of disability rights.

#### Lunch

#### <u>Legislating for Supported Decision-Making: New Legislative</u> <u>Innovations on Article 12</u>

#### Colombia: Chipping away at Substitute Decision-making, Multi-layered Strategies in Colombia

Andrea Parra, Director of PAIIS, University of Los Andes Law School, Colombia

### Bulgaria: Draft Legislation on Supported Decision-making in Bulgaria

Pavleta Alexieva, Program Director, Bulgarian Centre for Non-Profit Law, Bulgaria

#### **Ireland: Ireland's new Assisted Decision Making Act** (2015). A Compromise or Compromised? Dr Eilionóir Flynn, NUI Galway

#### Georgia: The 2014 Ruling From the Georgian Constitutional Court – Requiring the Ending of Guardianship and New Legislation on Supported Decisionmaking

Giorgi Dzneledze & Tamuna Nadiradze, Georgia, Coalition for Independent Living

**Interactive discussion** with the speakers and the audience led by John Wodatch on how to legislate for supporteddecision making lessons from the case studies

#### **Tea and Coffee Break**

<u>New Innovations on Securing the Right to Live</u> <u>Independently and be Included in the Community: Article</u> <u>19</u>

# Israel: How to Track and Measure 'Success' in the Deinstitutionalisation Process?

Dr Michal Soffer, Lecturer, University of Haifa

#### Georgia: Challenges in the Post-Soviet Zone

Giorgi Dzneledze & Tamuna Nadiradze, Georgia, Coalition for Independent Living

### Kenya: What Does Community Living Mean in Africa?

Elizabeth Kamundia, Doctoral Candidate, University of Pretoria, South Africa

# Europe: How to shift from the stubborn persistence of institutionalisation towards creating inclusive communities?

Magdi Birtha, Policy and Advocacy Officer at COFACE, the Confederation of Family Organisations in the European Union

#### Europe: Using European Taxpayer's Monies to End Institutionalisation – the New EU Structural Funds Regulations

Alexandra Hillen-Moore, Researcher, Centre for Disability Law and Policy, NUI Galway

**Interactive discussion** with the speakers and the audience led by John Wodatch on the topics discussed & the experiences of the participants.

# Small group breakout sessions – reflections from the participants on the day's proceedings

### Day 4: 23 June Topical Issue – Liberty (Article 14) & Retrospective Conversation with the Framers of the UN CRPD

**Rationale:** This is a day to focus on a contemporary issue that is consuming attention around the world and has not yet been crystalized/resolved. The issue concerns the right to liberty and when, *if ever*, liberty can be denied to a person with a disability. It affords space to stand back from the heat and try to generate some light so that people can define their own vantage points or positions. The aim is not to provide answers but to clarify the positions of main protagonists and to create a space for reflection on the part of the participants.

The afternoon will open up a unique space to hear from some of the drafters of the UN CRPD which is now nearly 10 years old.

Chair: Rosemary Kayess, University of New South Wales, Australia

#### **Report on breakout sessions from Day 3**

#### The Right to Liberty for Persons with Disabilities

**The Intentions of the Framers: What We Meant By the Right to Liberty During the Treaty Negotiations** Professor Amita Dhanda, National Academy of Legal Studies and Research (NALSAR), India

**Re-imagining Mental Health Law in the 21<sup>st</sup> Century** Jolijn Sentegoeds, Chairperson, Mind Rights, Netherlands

# The Perspective from the Office of the High Commissioner for Human Rights

Facundo Chavez Penillas, Human Rights & Disability Officer, UN Office of the High Commissioner for Human Rights, Switzerland

#### **Tea and Coffee Break**

**Interactive discussion** with the speakers as well as Elizabeth Kamundia & Alberto Vasquez led by Rosemary Kayess

#### Lunch

#### A Conversation With the Framers – Panel Discussion

This section – suggested by former faculty – brings together several faculty who had been active in the negotiations of the UN CRPD. It will hear about the roles they played and - more importantly - how their perspectives have evolved and changed in the intervening period. Where are they now – in civil society, with civil society, alongside civil society or acting more independently? Looking back and forward, what are their hopes and fears? How do they see the process of change – the expected and unexpected barriers?

**Rosemary Kayess**, University of New South Wales & former member of Australian Government delegation

Professor Amita Dhanda, NALSAR, India

**Osamu Nagese**, Visiting Professor, Ritsumeikan University, Japan & Regional Representative for Asia-Pacific, Inclusion International

**Professor Gabor Gombos**, Adjunct Professor, National Academy of Legal Studies and Research, India & Centre for Disability Law and Policy, NUI Galway

**Professor Gerard Quinn**, Centre for Disability Law and Policy, NUI Galway

#### **Tea and Coffee Break**

**Interactive discussion** with the speakers led by Elizabeth Kamundia

Breakout sessions to reflect on the day

#### **Report on breakout sessions from Day 4**

The Moot Court narrows down some hard general questions into net legal points. It forces people to think through their arguments and to pose them in a way that they hope will influence others who may not naturally agree.

Focus: This assumes a complaint under the Optional Protocol of the UN CRPD.

The exact Moot exercise will be emailed to registered participants two weeks before the Summer School is due to take place. It will likely focus on the legality of restrictions on the functioning of civil society.

**Judges:** Justice John MacMenamin, sitting judge of the Supreme Court of Ireland.

Professor Amita Dhanda, National Academy of Legal Studies and Research, India

Mr John Wodatch, Former Director of the Disability Section of the Civil Rights Division in the US Department of Justice

The teams will spend the morning of the 5<sup>th</sup> and last day in preparation.

Late morning is the competition itself. This will be followed by the deliberation by the judges, the announcement of the winning team, and the announcement of the best advocate.

Close & award of certificates: Senator John Dolan, Senate of Ireland