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Booklet of Abstracts

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A: The Right to Legal Capacity

Chair: Professor Phil Fennell (Cardiff Law School, University of Wales)

1. Tina Minkowitz (United States)
   Center for the Human Rights of Users and Survivors of Psychiatry
   “Alternatives to “Functional Capacity”: How to Operationalize the Right of Persons with Disabilities to Make Their Own Decisions”

The UN High Commissioner for Human Rights has emphasized that legal capacity is the right to make one’s own decisions. What then to make of the “functional” approach to legal capacity being promoted in many countries as compliance with Article 12? Functional capacity allows deprivation of the right to make decisions based on one person’s evaluation of another’s decision-making abilities. When framed as “mental capacity” it is even clearer that this constitutes discrimination based on disability. This paper will explore the underlying needs met by the traditional requirement of competence as an element of valid consent, and alternatives that do not infringe the autonomy of persons with disabilities.

2. Edurne García Iriarte (Ireland)
   Trinity College Dublin
   “People with intellectual disabilities’ own decisions?: Examination of challenges to the implementation of the UN Convention on the Rights of Persons with Disabilities”

The UN Convention on the Rights of Persons with Disabilities provides guidelines for the implementation of the convention through eight principles. The first of these principles is the “respect for the inherent dignity, autonomy, including the freedom to make one’s own decisions, and independence of persons.” While the importance of this principle is paramount for people with intellectual disabilities, its implementation is overtly complex. Many organizations providing services to people with intellectual disabilities embrace this principle within their mission. However, organizations often lack guidelines on how to facilitate decision making of their service recipients and people with intellectual disabilities frequently make decisions only in areas of scarce importance to them. In this presentation, three different types of challenges to allow people with intellectual disabilities to make their own decisions are examined: accountability requirements for organizations, support provided to people with intellectual disabilities, and underlying assumptions on the capacity
of people with intellectual disabilities to make decisions. First, accountability requirements for organizations regularly focus on decisions regarding needs rather than preferences of people with intellectual disabilities. Furthermore, organizations meet the accountability requirements by evidencing mere physical presence of people with intellectual disabilities when decisions are made. Second, people with intellectual disabilities often lack support to make their own decisions.

There is frequently lack of relevant information regarding the decisions people with intellectual disabilities make and this information, when it is available, is commonly inaccessible. Third, the underlying assumption of limited capacity of people with intellectual disabilities to make their own decisions is present at institutional and organizational levels. The analysis of these challenges will be presented through a case study conducted in a community-based organization providing services to people with intellectual disabilities in the United States. This presentation will reveal the influence that accountability requirements, support, and underlying assumptions have on people with intellectual disabilities when making their own decisions. Furthermore, it will highlight the importance to address these challenges if this theoretical principle is to evolve into a factual application.

3. Jitka Sinecká
   Mental Disability Advocacy Center, Budapest, Hungary
   Czech Republic: The right to vote and people deprived of legal capacity

The right to vote is one of the most fundamental rights of any democratic state. Yet, in a democratic state such as the Czech Republic, people with intellectual or psycho-social (mental health) disabilities who have been deprived of legal capacity, cannot vote or stand for election. The exercise of the right for persons deprived of legal capacity is restricted by Article 2(b) of the Act no. 247/1995, o volbách do Parlamentu České republiky (Law on Elections to the Parliament of the Czech Republic). The Constitutional Court of the Czech Republic may consider two cases of Mr. Hlaváč and Mr. Soldán, two people with diagnoses of psycho-social disability who want to vote, but are prohibited from doing so because they have been deprived of their legal capacity and placed under guardianship. If the Court decides before the Parliamentary elections in May 2010 it will enable more than 25,000 citizens (0.3% of all voters in the Czech Republic) to exercise their political right.

The Mental Disability Advocacy Center submitted an amicus curiae brief – a third party intervention – to the Constitutional Court in February 2010 to be of assistance to the Court in its decision on the instant two cases. This amicus brief provided the Czech Constitutional Court with legal context and international and comparative legal analysis. The amicus curiae brief particularly elaborated on the United Nations Convention on the Rights of Persons with Disabilities, as the Czech Republic has recently
ratified the treaty and it will be for the first time when a Constitutional Court is asked to interpret the Convention.

This presentation will firstly set out the Czech legal landscape with regard to the right to vote for people with real or perceived psycho-social (mental health) or intellectual disabilities. Further, it will argue against common assumptions that votes cast by people with psycho-social (mental health) or intellectual disabilities are “irrational”, “incompetent” or “manipulated”. The presentation will also provide several examples of countries with a more flexible and equitable approach to the right to vote for people under guardianship.

4. Maria Walls (Ireland)
Ph.d Fellow, Centre for Disability Law & Policy, NUI Galway

“In search of personhood – the potential impact of the Convention on the Rights of Persons with Disabilities”

To make this complex and fundamental change a reality, central concepts need to be reinterpreted. It includes overthrowing the history of paternalism and substitute decision making processes, reinforcing the capacity to act and exploring how to effectively support people in the decision-making processes. There are many challenges to be faced in this process of respecting the personhood of people with disabilities.

5. Jan Fiala (United States)
Harvard Law School (LL.M. candidate)

“The UNCRPD and legal capacity reform in Hungary – successes and failures”

Hungary was among the first countries to ratify the Convention on the Rights of Persons with Disabilities (CRPD), and the only one to reform its guardianship legislation since its ratification. This unique experience has important implications both for our understanding of Article 12 of the CRPD and guardianship reforms of other countries implementing it.

As a Legal Officer of the Mental Disability Advocacy Center (MDAC), I had the privilege to take part in the legal reform. I would like to draw on my experience as an advocate, and analyse the reform in a systemic way, suggesting strategies that would transpose the successes of the Hungarian experience to other jurisdictions without repeating its mistakes.

The new Hungarian guardianship legislation departs from the outdated understanding of legal capacity. It introduces supported decision-making as a legal institution to Hungarian law, with the necessary safeguards and procedures. The legal questions raised by this codification have posed a huge challenge to Hungarian civil law doctrines, and deserve special attention. At the same time, the law does not abolish guardianship, only seriously limits and redefines it using a strictly functional approach. The paradigm shift of Article 12 of the CRPD thus influenced, but is arguably
not fully implemented by the reform. Supported decision-making and guardianship will co-exist for an intermediary period. This conscious choice raises serious questions about the CRPD-compliance of the reform, and also about the nature of the CRPD itself. Future reforms aimed at the most progressive implementation of Article 12 should learn from the Hungarian experience and design strategies that recognize the need for practical, workable solutions in legal reform without compromising the CRPD’s aspirations.

Equally interesting as the new legislation was the process leading to its adoption. A coalition of disabled persons’ organizations played a major role in convincing the government to reform the guardianship system, and drafted the text of the law itself. The strategies used by the coalition to organize themselves around the issue of legal capacity and make their voice not only heard but also taken into account could be utilized in other countries as well.

The reliance on the CRPD played an important role in the reform’s success. Similarly important, however, was the influence of the European Court of Human Rights’ jurisprudence. The recent decision of Shtukaturov v. Russia significantly contributed to convincing the government about the necessity of abolishing plenary guardianship. The interplay between these two sets of international human rights norms will be crucial in shaping implementation and future reforms in Hungary. The Hungarian guardianship reform has been occasionally referred to, but nowhere described in depth in the legal literature. I will fill this gap by providing an analysis of the reform process and its outcome, and drawing the necessary conclusions for other countries contemplating bringing their guardianship legislation in line with the CRPD.

6. Sándor Gurbai (Hungary) (unable to attend)
Pázmány Péter Catholic University, Faculty of Law and Political Sciences

“From Civil Death to Visible Citizens - Legal capacity law reform in Hungary”

In Hungary May 2009 out of a population of approximately ten million (people), 67 480 adults were under guardianship, 43 734 of whom were under plenary guardianship and suffered civil death.

In my paper I present the process and examine the outcomes of the legal capacity law reform in Hungary through a comparative study of the relevant international human rights law and the provisions of the old and the new Hungarian legal capacity law.

In this context, I highlight the role of a very efficient civil society coalition and the Ombudsman in the changing process of the Hungarian Civil Code. I analyze the concept of legal capacity by reflecting the official Hungarian translation and by pointing out the aim of the CRPD. By examining the paradigm shift in Hungary, I systematically analyze the Hungarian legislation in contradiction, inter alia, with article 12 of the CRPD. I give prominence to the need for amendment of the Constitution, which
declares that the right to vote shall not be granted to persons who are under guardianship limiting or excluding their capacity. I underline the significance of the new, less restrictive legal measures (supported decision-making and advance directives) to guarantee that persons with disabilities enjoy legal capacity on an equal basis with others. I emphasize the importance of the abolishment of the total deprivation of a person’s legal capacity and of the term of partial guardianship of a general nature. I conclude my paper by describing the impacts of the legislative reform on people with autism, intellectual and psycho-social disabilities.

7. Catriona Moloney (Ireland) (unable to attend)
Legal Researcher, Law Reform Commission of Ireland

“Paternalism versus Autonomy: How to achieve a balance?”

The purpose of this paper is to examine how the law on capacity can achieve an appropriate balance between the traditional paternalistic protection given to vulnerable adults and the philosophical shift in policy towards an emphasis on autonomy, capacity and empowerment. This paper discusses the core issue in this debate: how to regulate in this area to ensure adequate protection for the vulnerable, while also providing sufficient freedom for them to practice the right to self-determination. Consequently, this implicates achieving a compromise between restricting personal rights, such as autonomy, liberty and dignity, and at the same time respecting these very rights. To facilitate a discussion of the latter issues the following will be examined in this paper:

• There will be a consideration of the current law on capacity and consent and how it affects people with mental health problems.
• The paper will concentrate on the innovative shift from the medical model towards a social human rights perspective for people with mental disabilities. The paper will discuss the International Bill of Human Rights, the United Nations Convention on the Rights of Persons with Disabilities, principles of the WHO and the Mental Illness Principles as set out by the United Nations General Assembly. The paper will also focus on how the European Convention on Human Rights is interpreted by the European Court of Human Rights to provide protection for or to promote the human rights of mentally disabled people.
• The paper will examine the development of a human rights approach in Australia, Canada and the United Kingdom. (Further research will include developments in Sweden, Germany and Israel.)
• Finally, the paper will look at Ireland’s efforts to comply with international human rights obligations. Therefore, there will be an analysis of the Irish attempt to achieve a balance between protecting the best interests of the vulnerable and complying with the philosophical shift towards emphasising autonomy, capacity and empowerment.
B: The Right to Independent Living

Chair: Madeline Clarke (Executive Director, the Person Centre)

1. Tirza Leibowitz (United States)
   Director of Advocacy Survivor Corps
   “Living in the Community – Disentangling and Materializing the Core Right”

CRPD Article 19 opened doorways to an array of legal tools for promoting the right to live in the community. Its core components include the inalienable right to live in the community that is not subject to proving one’s ‘ability’ to do so, from which follows states’ obligation to provide services to facilitate living in the community; and recognition of the human rights violations inherent in the institutional way of life, regardless of the existence of lavish conditions in institutions or the absence of degrading ones.

Yet these components are often subsumed by sister-rights, such as freedom from torture, freedom of movement, and liberty and security. This may happen when the focus of the case is forced placement or torture and abuse in institutions, resulting in problematic implications: If arguments negating institutional life per se remain covert, the message of the non-normative nature of institutions is in danger of becoming blurred. Carrying out improvements to remedy atrocious conditions in institutions may wind up in their endorsement once improved. Abandoning Article 19’s directive to run a system that supports life in the community, independently of the issue of de-institutionalization, may leave intact support lines that nourish an institution-biased system, and perpetuate the misconception that ‘ability’ must be proved in order to merit living in the community.

A number of cases currently or recently litigated (From Israel, Paraguay, Romania, and the US) will be analyzed through the lens of these quandaries, some domestic and others litigated in international courts. Some directly demand the means for living in the community, while in others the main thrust is challenging abuse in institutions. The purpose of the analysis is to extract principles that can guide human rights advocates through the dilemmas they will encounter in implementing this right, with a focus on:

- How to counter abuses in institutions while avoiding the trap of endorsing them. Given the millions of individuals currently living in institutions, most of whom are unable, or have been stripped of the ability, to stand up for their rights, the door cannot be shut on Article 19 cases targeting abuses in institutions.
- How to make living in the community relevant in contexts common to many developing countries, where the case isn’t so much the proliferation of institutions – in fact individuals live with their families, albeit with no support whatsoever – as much as lack of
services for the general community (e.g. water, medical care, education). No institutions exist to serve as the basis for the argument that their entitlement for support within an institution should be provided instead in the community. At the same time, the lack of community infrastructure strains the possibility to resort to equality with the general population as grounds for the case. These dilemmas underscore the duty to instill life into CRPD Article 19.

The proposed paper will attempt to do so, thereby helping remove the article, and the people whose rights it is intended to protect, from the margins to the spotlight of human rights action.

2. Noeline Fox (Ireland)
Ph.d Fellow, Centre for Disability Law & Policy, NUI Galway

“Independent Living – the Potential of the European Court of Human Rights”

For the first time in international law the right to independent living for people with disabilities was recognised in Article 19 of the UN Convention on the Rights of Persons with Disabilities. Translating this right into practice at national level remains a challenge for legislators and policy makers. This paper will examine the potential of the European Court of Human Rights and the European Convention on Human Rights to assist in the recognition and realisation of the right to Independent/community living in Europe. Specifically it will review the case law of the Court relating to Article 5 (Right to Freedom and Security), Article 8 (Right to respect for private and family life) and Article 14 (Prohibition of discrimination) as they relate to disabled people. The paper will briefly look at how the definitions of ‘detention’ and ‘private life’ emerging from the Court apply to the situation of people with intellectual disabilities and mental illness in state funded residential care in Ireland.

Whether and how the core elements of the right to independent living can be read into the Convention will be examined in the light of the emerging international consensus of the existence of such a right as reflected in the Disability Convention and other UN Human Rights instruments and policies, and the policies of the European Union and Council of Europe relating to disability. To date the Court has been reticent about imposing positive obligations on States particularly in relation to Article 8, where such obligations may involve either the expenditure of limited national resources or could be interpreted as representing an interference with the setting of national economic or social priorities by governments. The paper will explore possible means of assisting the Court to move beyond this conservative reading of the Convention by looking at:

- The need to establish more concrete limits to positive obligations so that wholesale measures involving vast expenditure by governments can be avoided
• The potential of ‘reasonable accommodation’ to facilitate the realisation of the right to independent living under the Convention – particularly in relation to Article 8.
• The possibility of convincing the Court that institutionalisation of people with disabilities in itself represents discrimination and is a violation of human rights. How the issue of indirect discrimination, prohibited under Article 14, could drive forward the recognition of the right to independent living and move service/support systems towards adopting this as the default position.

3. Elham Youssefian (United Kingdom)
London School of Economics

“Implementation of the right to privacy of people with disabilities in developing countries”

People in developing countries more frequently experience arbitrary and unlawful interference with their private and family lives as a consequence of their disability. This paper discusses the legal, cultural, economic and social barriers which have prevented or hindered the full or even relative implementation of the right to privacy of those with disabilities living in developing countries. The paper also introduces some legislative, regulative and policy options to address these barriers.

In the first part of this paper, I demonstrate how the living conditions of a person with a disability in a developing country context may result in the frequent or even systematic denial of his or her privacy in many ways. I argue that the right to privacy of such people is made extremely vulnerable to the inevitable interference and potential violation by those supporting them, including family members, friends and those who interact with and provide any sort of special assistance to them. I also consider the relationship of the right to privacy with other human rights contained in the UN Convention on the Rights of People with Disabilities (‘UNCRPD’) and argue that this interdependence between human rights is more pronounced in a disability context. In this regard, I specifically explore the relationship between the right to privacy of people with disabilities and the right to enjoy an independent life, the right to access, the right to mobility and the right to development.

In the second part of the paper, I outline and critically evaluate different measures necessary to implement Article 22 of the UNCRPD, which recognizes the right to private life of people with disabilities. In doing so, I emphasise the importance of the three dimensions of State obligation; the duty to respect, protect and fulfil, as fundamental to the implantation of special measures necessary to achieve equality between people with disabilities and those without in the realisation of the right to privacy.

4. Andrew Power (Ireland)
Researcher, Centre for Disability Law & Policy, NUI Galway
“Self-Determining Options: Comparative Perspectives in Independent Living Law & Policy”

This paper examines emerging models of Independent Living which are reshaping welfare states to give persons with disabilities more choice in self-determining their own support. These models are characterized in many western jurisdictions by self-determination, personalized support and choice in planning one’s own living arrangements and support packages to become independent in the community. This is reflected in the goals of Article 19 of the UN CRPD (Living independently and being included in the community) which calls on States Parties to take effective and appropriate measures to ensuring that persons with disabilities have the opportunity to choose their place of residence, and have access to a range of in-, residential and other community support services, including personal assistance necessary to support living and inclusion in the community. Using comparative perspectives, from the US, Canada and the UK, this paper focuses on the legislative, regulatory and policy options behind some of the transformation efforts. It identifies the challenges of moving from traditional models of welfare which have enforced many people into dependency towards individualized support models which encourage independence.

5. Sinead O’Donnell (Ireland)
LL.M Research Candidate, Centre for Disability Law & Policy, NUI Galway

“Article 19 Comparisons of those living independently and those not: The effect of care provision”

I have yet to find an adequate definition of community. From an inclusionary perspective one can identify mutual benefits in that the people in the community who are latterly affected by disability in their own lives will have immediate communal aspirations. The general public may have the perception that people with disabilities are visible in the community but I am more concerned at the services being provided to the people and how effective they are rather than visability and distribution within the community. I believe If you feel responsible to a community you are more likely to participate in it and that the community at large benefits from integration of people with disabilities. When you become an active person in society, society benefits, you become contributory to all costs via tax and general involvement in society. The only way to achieve this situation is to provide adequate services.

Once ratified by all countries, the United Nations Convention on Persons with Disabilities and Optional Protocol will be a reference point for people living and working in the area of community development. Article 19 is yet to be tested as to how useful it can be. If you ratify it or don’t there is no set strategy of implementation. Is it contradictory? It has the opportunity to be ground breaking and change the landscape if implemented fully.
There are many aspects to look at when comparing those living independently with those who are not. While some may say that funding is paramount when balancing the books etc. I intend to take a holistic approach that includes health, wellbeing, self esteem and self worth as well as the economic perspective. Disability being such a broad area, Service Provision is crucial to this. If a good service is provided it is good for the community as a whole. One benefits if your service is of good quality it places less demands on other services, wherein less insecurities arise from poor services.

Article 19 is the first place where Independent living is set out in an international human rights document, and may prove a potential touchstone on independent living. Given the significance of Article 19, will this help the area of service provision and/or care provision grow or will there be a return to the medical model/mass management? How many service providers take a completely person centred approach to planning their service provision? Are they promoting their idea of a person centred focus rather than the users view of their own service, particularly as more resources may be used when the person is consulted and they maybe avoiding more issues being ironed out as a result?
C: Towards Effective National Strategies for the Implementation of the UNCRPD (1)

Chair: Professor Gerard Quinn (Centre for Disability Law & Policy, NUI, Galway)

1. Eilionóir Flynn (Ireland)
   Researcher, Centre for Disability Law & Policy, NUI Galway

   “Taking the Convention on the Rights of Persons with Disabilities to the Next Level: Domestic Implementation and National Disability Strategies”

Since the entry into force of the Convention on the Rights of Persons with Disabilities (CRPD), the global need to move beyond formal guarantees of equality towards proactive measures which improve the daily lives of people with disabilities is more apparent than ever. In this context, many countries, including Ireland, have developed National Disability Strategies which set out how people with disabilities are to be included in society as fully participating citizens; through measures to improve access to education, employment, transport, housing, income and personal support, etc. Now that these strategies have been formulated, it is crucial to find the best means of implementing them, in order to ensure that their aims are realised and that they can bring about change at grassroots level, rather than allowing strategies to be regarded merely as aspirational policy documents.

This paper will explore a number of guidelines for developing National Disability Strategies, which are derived from the drafting process of the CRPD, as well as those, which appear in the final text. Building on the CRPD’s core values of autonomy, dignity, participation and solidarity, the paper will also highlight critical success factors in strategy implementation emerging from new governance and community development literature. This combination of approaches aims to devise recommendations on various aspects of strategy development including:

- meaningful involvement of people with disabilities and disability communities,
- engagement with national, regional and international human rights mechanisms,
- the ability to measure progress in life outcomes for people with disabilities using statistical information across a range of sectors,
- dedicated implementation systems with opportunities for open engagement with the public on measures taken and
- independent monitoring to evaluate the success of the strategy as a whole.

This paper will examine the approaches taken by a number of jurisdictions in developing these aspects in their National Disability Strategies in order
to highlight best practice in implementation and monitoring of the CRPD at domestic level.

2. Anna Bruce (Sweden)
Faculty of Law, Lund University and Raoul Wallenberg Institute of Human Rights and Humanitarian Law

"The Potential of Legal Standards of Equality and Non-discrimination in CRPD – Friend, Foe or Largely Superfluous?"

CRPD is the first human rights instruments to protect the entitlements of a group both by minimum standards (compare CRC) and by a relative standard of equality and non-discrimination on the particular ground identifying the constituency (compare CEDAW). As every situation or issue relevant to CRPD potentially actualises comparison (as it concerns members of a group) one of the consequences of this legal construction is that every situation or issue covered by a minimum standard can also be approached through the standard of equality and non-discrimination (as long as the level of enjoyment in question is enjoyed by others outside that group). This comparative core of CRPD is visible on a general level through the conceptual overlap between the concept of disability (Article 1) and the concept of discrimination (Article 2). Albeit the former addresses “participation in society” and the latter “human rights and fundamental freedom”, they both define their standard of enjoyment as “on an equal basis with others”.

While the protection provided by the minimum standards framework in CRPD thus largely overlaps with protection from the equality and non-discrimination framework, this is not a reciprocal relationship. The reach of Article 5 clearly exceeds the minimum standards in CRPD, both ratione personae (by covering discrimination by association) and ratione materiae (by applying to “all human rights and fundamental freedoms”). In addition, through the construction of general obligations in Article 4(2), economic, social or cultural issues framed as discrimination arguable circumvents the subjection to progressive realisation. Potentially even more importantly, Article 5 provides protection from comparative injustice above the guarantees set by the minimum standards. However, these well known functions of the equality and non-discrimination

3. Maria Walls (Ireland)
Ph.d Fellow, Centre for Disability Law & Policy, NUI Galway

“Comparative analysis on the implementation of the United Nations Convention on the Rights of Persons with Disabilities across diverse jurisdictions – initial reflections”

More than 144 States have now ratified the Convention on the Rights of Persons with Disabilities. This paper explores the initial reflections on the process of signing and ratifying the Convention within New Zealand, USA, the People’s Republic of China and the Republic of Ireland. This includes
the engagement of each state in the drafting process, the process undertaken to consider each State's engagement in the ratification process and reflections on some key success factors on this journey.

4. Mona M. Abdeljawad (Jordan)
   Assistant Secretary General for Technical Affairs, Higher Council for the Affairs of Persons with Disabilities, Amman, Jordan

   "Effective Implementation Mechanisms – A Case Study from Jordan."

This paper examines Jordan as a case study of legal measures taken to give effect to the Convention on the Rights of Persons with Disabilities (CRPD); it also reviews the core feature of its national implementation mechanism and provides a set of lessons learnt, conclusions and recommendations for the effective implementation of the CRPD.

Chapter one provides a historical overview of the process of adoption and ratification of the CPRD. Jordan has signed and ratified the CRPD in the years 2007 and 2008 consecutively. In 2007 Jordan has taken three major steps by which an enforcement mechanism was created to implement the Convention. The National Disability Strategy was developed, the Law on the Rights of Persons with Disabilities #31 for the year 2007 was adopted, and the Higher Council for the Affairs of Persons with Disabilities (HCAPD) was created. This chapter outlines the main features of the above mentioned Strategy, Law, and the role and mandate of the Council.

Chapter two provides an overview of a national consultative process to review the implementation of the first phase of the Strategy. An analysis of the gaps and priorities are outlined. A synopsis of the role of a national coordination mechanism is also examined, in addition to major challenges to its effective functioning.

Chapter three examines measures taken to establish national monitoring mechanism. It outlines the composition, role and mandate of the National Monitoring Committee thus far. The chapter also examines Jordan obligations to implanting article 33.3 of the CRPD; the status of DPO organizations in Jordan and challenges faced. The paper concludes with main recommendations and lessons learnt on the effective implementation of article 33 of the CRPD.
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C: Towards Effective National Strategies for the Implementation of the UNCRPD (2)

Chair: Professor Gerard Quinn (Centre for Disability Law & Policy, NUI, Galway)

1. Heather Aldersey
   The University of Kansas, Beach Center on Family and Disability

   "Frameworks and Taxonomies: Identifying Opportunities in Policy Improvement: The United States’ Individuals with Disabilities. Education Act and the United Republic of Tanzania’s National Policy on Disability"

Policy documents are the backbone of democracies: they help to guide the governmental decision-making process, hold governments accountable for promises made, and shape societal viewpoints and actions. Oftentimes, the challenge for government is to create a policy that both affirms the rights of people with disabilities and offers concrete applications for translating policy into practice. Countries that have more experience with disability policy and action should be called upon to share experiences and lessons learned with nations that are in the earlier stages of official disability public policy in order to ensure that new disability policy serves nationals effectively and efficiently.

The government of the United States of America has been creating and improving upon policies addressing the rights of people with disabilities for over thirty years and the Individuals with Disabilities Education Act (IDEA) is a ground-breaking policy document that has become the basis for action and decision-making on disability in the United States – both for government and for general society. Much scholarship, research, and debate has shaped and developed IDEA over time.

The United Republic of Tanzania’s National Policy on Disability of July 2004 is an example of a policy document that represents a great step toward improving the lives of people with disabilities yet lacks a structure that offers a concrete plan of action for translating overall goals and aspirations into reality. In this paper, we apply disability policy analysis frameworks and taxonomies - created by years of public policy research and legal advocacy at the Beach Center on Family and Disability at the University of Kansas – to Tanzania’s National Policy on Disability. We apply framework and taxonomy to help structure an outline of the key aspects of NPD policy and offer suggestions for improvements in future reauthorizations. Given that Tanzania acknowledges that policy addressing people with disabilities is a relatively new for the country and that “there is a need for Tanzania to learn from countries experienced in this service area” (NPD 3.26), we hope that a comparison of IDEA and NPD will be of value to those who develop and reauthorize Tanzania’s future disability policies.
In May 2008, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) entered into force. As international law, this legislation requires monitoring of legislative and programmatic progress, creating a need for international research on the rights of persons with disabilities. To date, little research has focused on international differences in the current rights of persons with disabilities and the relationship of those rights to self-determination and quality of life. 58 persons with disabilities in three countries: Nepal, Zambia, and the United States were surveyed. Participants were members of disability umbrella organizations participating in the human rights education program, Human Rights. YES!, who completed surveys regarding various demographic characteristics, quality of life, self-determination, and human rights. Using chi-square analyses, the three country samples were found to have demographic differences on several variables: age, disability, education, community size, housing, civil status, and previous advocacy experience.

Countries were found to differ significantly in their ratings of quality of life, self-determination, and personal human rights, but not on country support of human rights. In respect to quality of life, the US scored significantly higher than both Nepal and Zambia and in respect to ratings of self-determination and personal human rights, the US scored significantly higher than Zambia. Quality of life was highly correlated with previous advocacy experience, type of schooling, employment, housing, self-determination and human rights. Multiple regression analyses indicated that self-determination, employment, and previous advocacy experience were significant predictors of quality of life. Personal human rights was a significant predictor of self-determination.

These results replicate existing literature which cites self-determination as predictive of quality of life and they are consistent with the topological model of quality of life for cross-cultural understanding. This study shows that through the coordinated improvement of multiple factors: self-determination and advocacy (personal factors), employment (material factors), and human rights (social factors), the quality of life of persons with disabilities may be improved.

The purpose the Human Rights. YES! program was to enhance understanding of the UNCRPD and to provide an explanation of democracy and citizen participation in political and public life as well as greater engagement in disability rights work by civil society organizations, including disabled peoples organizations. Research focused on the
applicability of this program model to the monitoring of UNCRPD and informing policy and program development will be discussed.

3. David Shannon (United Kingdom)
Faculty of Law, University of Leeds


Through the use of the consensus framework for rights promotion established by The United Nations Convention on the Rights of Disabled Persons a comparative analysis will be developed to determine how these rights are made normative by judicial and quasi judicial bodies in Ontario. The purpose of this study is to identify the “best judiciary practices”. These best judicial practices would presume to be put forward as a model for consideration as the most effective means of enforcing and promoting disability rights in the Courts, and ultimately assisting in realizing dignity and equality for individuals living with a disability.

It has been argued that 1981 marked a seminal change in the way that disability was articulated and or perceived at a global level. This marked the United Nations “Year of the Person With a Disability” and the publication of the “World Program of Action”. Twenty five years later another arguably significant marker was achieved with the signing by several UN member states of the Convention on The Rights Of Persons With Disabilities.(UNCRPD) This is believed by many to have created a “paradigm shift”. That is, the medical model of disability, where disability was defined by an individuated bio-medical subordinated self, has been replaced with a view that disability is a personal affect deserving of human rights protection. It may be further argued that the UNCRPD has created a broad rights framework that should be informative to judicial and quasi judicial bodies in major jurisdictions.

Consistent with the evolution of a rights based approach within the UN framework, the broad central premise behind contemporary disability rights legislation at an international and domestic level has been to guarantee the dignity and equality of all persons with a disability. To achieve this end judicial and quasi judicial bodies in many jurisdictions including Ontario have taken a combination of approaches, such as equality of opportunity, the duty to accommodate and a systemic approach through periodic report submission. While showing some dissimilarity these dominant themes thread throughout approaches to disability rights that have been taken by the UK, Canada, USA, UN and many other jurisdictions.

The practices adopted by judicial and quasi judicial bodies in Ontario requires further analysis and comparison in order to the realize dignity and equality for persons with a disability. What has succeeded? What has failed? Where do the gaps remain? Answering these questions will facilitate the discourse and knowledge translation among stake holders working toward the advancement of disability rights and greater inclusion.
of all persons with a disability. This study is designed to improve the rights of persons with disabilities through the judiciary, hence the psycho-social and medical potential of this same population. The development of an even more progressive model of rights for persons with disabilities fits well in many jurisdictions. Although not measurable in all instances, certain rights are a known factor in improving health, longevity and socio-economic development.

This project will also contribute to the critical assessment of existing knowledge on disability rights promotion and social inclusion of Persons with Disabilities in several jurisdictions in order to identify necessary directions for future research, and advance a close working relationship between disabled persons organizations, researchers, academics, lawyers and jurists. This paper will identify 1) the limitations and delimitations within the study; 2) the methodology to be used to gain, mobilize and analyse the data; and 3) the methodology to determine “best judicial practices”.

D: Definitions of Disability

Chair: Professor Mark Priestly (School of Sociology and Social Policy, University of Leeds)

1. Lisa Vanhala (United Kingdom)
   British Academy Post-Doctoral Fellow, Centre for Socio-legal Studies, University of Oxford

   “Twenty-five Years of Disability Equality? Interpreting Disability Rights in the Supreme Court of Canada”

This article explores the issue of disability equality in the Canadian context. It probes the ways in which the equality promises contained within the Charter of Rights and Freedoms have been interpreted by the Supreme Court of Canada in addressing disability issues. These range from discrimination in employment to inclusive education to end of life decision-making. Drawing on legal cases brought by both disabled and non-disabled citizens the article examines the extent to which the Court has recognized disability as a social construction. Relying on socio-legal analyses incorporating the perspectives of disability rights activists and their allies the article finds the evolution of a substantive approach to equality for disabled persons has been (and continues to be) one of fits and starts. It will suggest some lessons to be learned from the Canadian experience that should be considered when implementing and enforcing the provisions of the UN Convention.
In a federal system like the United States, there are tangible limits on the federal government’s power to remedy discrimination. Racial and ethnic discrimination was the predominant evil against which the Fourteenth Amendment was directed in 1868. That scope has since expanded certainly to religious and sex discrimination and presumably also to age and sexual orientation discrimination. Section 5 of the Amendment gives Congress the power to “enforce” the Amendment’s equal protection and due process guarantees. As the scope of that Amendment evolves along with the notion of human dignity, so must the power of Congress be enhanced under Section 5. Under the Commerce Clause of Article I of the Constitution too, federal disability discrimination laws pass muster. Disability discrimination in HIV cases under the Americans with Disabilities Act (ADA) diminishes employees’ productivity and constitutes a commercial exercise of federal regulatory power.

The traditional tripartite test (federal regulation of local commercial activity; cumulative effect of a local activity; deferential review by courts) sustains the exercise of federal commerce power. The strict application of the “congruence and proportionality” criteria (between the activity and its relation to human dignity under the Fourteenth Amendment) should be replaced by a more relaxed definition of “disability.” When Congress chooses to expand the scope of “We the People,” courts should review the exercise deferentially. This evolving understanding of the federal power to regulate disability discrimination goes hand in hand with the evolving definition of disability itself. HIV cases quintessentially reflect this evolution in the understanding of “disability.”

Despite the criticisms leveled by disability scholar Samuel Bagenstos, the United States Supreme Court in Bragdon v. Abbott, Sutton v. United Air Lines, Murphy v. United Parcel Service, Albertson’s, Inc. v. Kirkingburg, and Toyota Motor Manufacturing v. Williams has been entirely consistent in slotting HIV cases into the category of “present disability” — “a physical or mental impairment that substantially limits one or more . . . major life activities.” In litigious America, surely a constitutional challenge will make its way up to the Supreme Court challenging federal power in this area. The Court should realize the reality of an evolving understanding of disabilities built into the ADA’s text, and construe and uphold the Act accordingly.
3. Satoshi Kawashima (Japan)
Project Researcher, Graduate School of Economics,
University of Tokyo

“Coexistence of the minority and universal models of
disability: Is it possible in UNCRPD?”

The preamble of the Convention on the Rights of Persons with Disabilities (CRPD) recognizes "that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others." This conception, which is based on the social model of disability, can theoretically be interpreted in terms of the two concepts: the minority and universal models of disability.

UN General Assembly resolution 56/168, which established an Ad Hoc Committee on the CRPD, used the phrase "600 million persons with disabilities around the world" in its preamble. This is in line with the concept of the minority model being proposed as an underlying idea of discrimination law by many scholars. On the other hand, Irving Zola considers disability (impairment) as a normal human trait which almost everyone experiences. This is the universal model, which is said to be in conflict with the minority model.

In this article I explore the potential for coexistence of these two models, and explain in what sense it is possible and valid, using the concrete examples of non-discrimination and positive action (in particular the quota system), in the context of CRPD. This example is not only theoretically but practically important since the definition of disability in discrimination law and positive action has been discussed intensively, especially during the last 20 years. Theresia Degener insists, from the perspective of the social model, that we should not refrain from using medical terms when defining disability in discrimination law. In a recent article I agreed with her, and further proposed that the definition should be based on the universal model instead of the minority model so that courts may focus on not impairment but discrimination in accordance with the social model.

On the other hand I argue in this article that the definition of disability in the context of the quota system should be based on the minority model. The targeted persons under the quota system, which is admitted as a temporally measure to practically and effectively remedy the present effects of past oppression, should be not all individuals with impairments which are nearly universal personal traits, but rather certain groups with impairments who have been collectively and historically oppressed. The quota system as a measure for social justice should focus on the systemic disadvantage shared by certain persons with impairments, and thus should be based on the minority model. The minority model consists of various sub-minority-models that reflect different collective experiences of disability resulting from the complex interactions between persons with impairments and social barriers.
The validity of the two models depends on the objects and contexts of various provisions and clauses of the CRPD, such as non-discrimination or positive action, as do the validity of specific definitions of disability. In this sense the minority and universal models can in theory coexist. We should not use only one of the two models in implementing the CRPD.

**E: Civil Society – Nothing About Us Without Us**

**Chair:** Dr. Maya Sabatello (Center for Global Affairs, New York University)

1. Iris Elliott (Ireland)
   Ph.d Candidate, National University of Ireland, Galway

   “Civil Society Engagement with UN Treaties: inter sectoral learning from women human rights activists in Ireland”

Activists in Ireland have substantial expertise in the use of UN Treaties (as part of an integrated human rights strategy) to lever change in the domestic arena. We have also developed significant critiques of the limitations of Treaty implementation and monitoring. Therefore we are pro-actively exploring how to both work the existing Treaty system, and also investigate the potential of new mechanisms such as the Universal Periodic Review. Employing emancipatory, feminist and critical theory methodologies, the study reported in this paper understands human rights to be potentially transformative local-global dialogical and contentious spaces. Within these spaces human rights activists can: re-frame agendas, raise awareness, empower themselves and wider society, build solidarity (domestically and globally), lobby for change, hold States to account, and evolve counter-hegemonic discourses of human rights.

Given the Irish State’s hegemonic construction of human rights as external and ‘north of the border’, this paper asserts the importance of using human rights instruments to change the lives of people living within Ireland, whilst affirming and evolving relationships of mutual solidarity through transnational activism. Since the 1990s feminists in Ireland and globally have re-framed women’s rights as human rights. This paper reports on a doctoral study into the Women’s Human Rights Alliance, a feminist civil society entity that brings together traditional human rights and inter-sectoral women’s organizations in order to use the UN Treaty Body system to progress women’s rights in Ireland. Reflecting on the WHRA’s past work around CEDAW and current preparation of a gender shadow report on CESCR, this paper considers the potential learning and solidarity that could develop across civil society groupings of human rights activists.

Using feminist socio-legal and social movement theoretical frameworks, it describes the processes of meaning making and cultural re-signification undertaken by the WHRA to make international instruments relevant and useful to its broad-based constituencies including disabled women. These
processes are central to the WHRA’s creative, emancipatory shadow reporting methodology that enables it to scale shift local women’s rights claims into international arenas. Drawing on my experience in national disability policy work, the paper concludes by proposing that this is one civil society model that could inform national-level alliance building to progress disabled people’s human rights not only around the United Nations Convention on the Rights of Persons with Disabilities, but all UN human rights venues.

2. Valerie Karr (United States)
Adelphi University & The Victor Pineda Foundation

“It’s About Ability: Engaging youth in human rights education and advocacy”

According to Ban Ki-Moon, Secretary General of the United Nations, “There is a growing consensus that education in and for human rights is essential and can contribute to both the reduction of human rights violations and the building of free and peaceful societies. Human rights education is also increasingly recognized as an effective strategy to prevent human rights abuses.” The Victor Pineda Foundation dedicates a large amount of its time working at the grassroots level; sharing of our experiences, research findings and fieldwork with policy makers, opinion leaders, and peer educators. These approaches have helped us achieve our ultimate goal of helping improve conditions and advocacy for young people with disabilities.

"It's About Ability - An explanation of the Convention on the Rights of Persons with Disabilities" was developed in partnership with UNICEF. It is a learning guide for children, with or without disabilities, towards fighting exclusion and discrimination in society and promoting the Convention’s principles. The book and its learning guide highlight steps and actions governments must take to help children with disabilities realize their rights. Designed to empower children and young people aged 12–18 to speak out on the convention and become advocates for inclusion in their communities, the learning guide offers lesson plans and suggested activities to be used by young leaders, peer educators, teachers and other educators at the community level.

It’s About Ability Workshops provide human rights training to facilitators, young people and peer educators with a research-oriented approach. This presentation will review a recent training and project that took place in Guyana in cooperation with UNICEF, the National Commission on Disability (NCD), the Community-Based Rehabilitation Program (CBR), and the Organizations of Persons with Disabilities. The It’s About Ability Facilitator Training Workshop is an experiential workshop that reviews the principles of human rights education, effective facilitation techniques, and the foundations for promoting youth leadership using the It’s About Ability Model.
At this moment, it is possible to imagine children with disabilities in developing countries who, if focused on at the very beginning of their lives, could become a new generation of leaders promoting a wide range of civil and social rights, and thus becoming models of empowerment and creators of opportunities for future generations. This presentation will explore this method of human rights education through an in-depth analysis of the Guyana case study and implications for future dissemination and use.

F: Intersectionality of Disability: Gender, Indigenous Peoples, Age

Chair: Dr. Nata Duvvury (Co-Director, Global Women’s Studies Programme, NUI Galway)

1. Mary Keogh (Ireland)
   Ph.d Fellow, Centre for Disability Law & Policy, NUI Galway

   “Can an intersectional approach free disability from its traditional confines? The potential of using intersectionality to analyse the needs of disabled women in a development context”

Intersectionality, as a research tool had its origins with black feminist research, and it gave feminist researchers the lens to go beyond issues specific to women and look at how the intersection with different cultures and identities can marginalize women. As a analytical tool it goes deeper than a single identity or unitary analysis and takes into account the historical, social and political context and recognises that the experience of the individual based on the intersection of all relevant grounds.

The Convention on the Rights of People with Disabilities promotes a holistic understanding of disability and recognises where disability intersects with other identities such as gender and how this can perpetuate discrimination on a number of grounds. An intersectional approach has particular relevance in planning for effective development policy and programmes for disabled women.

Disability and gender in the developing world are inextricably linked studies show that gender can be considered a risk for acquiring a disability. The World Health Organisation estimates that more than 30 women every minute are seriously injured or disabled during labor, thus rendering vast numbers of women in the developing world physically and socially disabled. For every woman who dies from complications of pregnancy, between 30 and 100 more live with painful and debilitating consequences. Equally, disabled women are excluded from the majority of development interventions due to the fact they are disabled and also a woman. The limited statistics available show that literacy rate for women with disabilities may be as low as 1% (UNDP); mortality rates amongst girls with disabilities are much higher than for boys with disabilities (USAID, UNICEF).
The challenge with researching different identities experience in complex environments particularly developing countries requires looking through a wider lens than simply adding one identity to another. Groce claims that policies within a development context either focus on ‘disability’ or on ‘women’ rather than on the common problems shared by both and because of this women with disabilities have been disenfranchised from disability and mainstream development or gender policy. Intersectional work goes beyond designing policies that create small improvements for a defined percentage of a group and looks at how policies can ensure that all members of any marginalised group are enabled to empower themselves.

This paper investigates the potential of using the intersectional approach for analysing disability in a development context. By introducing an intersectional analysis, it will argue that we can start to move away from the traditional confines of disability analysis and look instead to a holistic analysis, which takes into account the social, historical and political context and better positions us for effective policy responses to disability within a development context, particularly for disabled women.

2. Barbara Claudia Phillips (Switzerland)
Swiss Paraplegic Research

"Raising awareness about awareness: insights from the feminist movement on interpreting Article 8 CRPD"

Art. 8 CRPD requires States Parties “to raise awareness throughout society ... for the rights and dignity of persons with disabilities”. This paper will suggest an interpretation of “awareness” that emphasises the difference between awareness raising and consciousness raising: In this paper, “awareness raising” means raising public awareness of disability issues whereas “consciousness raising” is addressed directly to the need to raise awareness among the oppressed group, in this case disabled persons.

By considering its history and analysing the wording of Art 8. CRPD we will show that consciousness raising as adopted by the second wave feminist movement (1960s & 1970s) is equally as important for the disability movement as is awareness raising. People with disabilities are not always aware of their own rights or of their oppressed position in society. Specifically, people with disabilities may not be aware of the CRPD as a new tool for expressing and hopefully enforcing their rights, especially their social and economic rights. We will take as an example of the need to emphasise the political importance of consciousness raising, the often quoted 1969 paper of Carol Hanisch entitled “The personal is political”. Hanisch argues that consciousness raising empowered the feminist movement, and by analogy we will make a parallel argument for its importance to people with disabilities. People with disabilities need not look only for personal solutions to their problems but should also be made aware, by means of consciousness raising activities, of the fact that their personal struggles are also political ones.
In addition, the analogy between the feminist movement and the disability rights movement reveals an important mistake that the feminists needed to learn from and which the disability movement should avoid: failure to see the importance of diversity and difference within the group. Feminists were criticised for not taking the diversity among women into account, ignoring the concerns of women of colour and disabled women. They only became aware of this problem after the first few years of feminist work. Just as women are not a homogenous group, neither are people with disabilities. They are not necessarily striving for the same things. There is power in numbers, but the different groups of people with different disabilities need to be very aware of their own diversity. This fact makes it essential to provide States Parties with an interpretation of Article 8 CRPD that includes consciousness raising as well as awareness raising.

3. Vered Shenaar Golan (Israel)
University of Haifa, Faculty of Social Welfare & Health Science, School of Social Work

“The Well-Being of Women with Disabilities Participating in Vocational Programs”

The dissertation examines the well-being of women with disabilities in the broad context of the person-in-environment paradigm. This paradigm sees the person and his various life environments as an interactive ecosystem, in which the individual and his environments simultaneously and mutually affect each other.

Within this framework, the central research question that arises is whether and to what extent environmental and personal factors, separately and combined, affect the well-being of people with disabilities. Discussing well-being in the context of the research population accentuates the importance of examining two main issues: the first relates to the type of interactions women with disabilities have with their economic and social environment, and as compared with the interactions experienced by women without disabilities; the second issue deals with the significance of life satisfaction as experienced by women with disabilities.

Acknowledging the importance of such mutual interactions is expressed both practically and theoretically. At the practical level, during the last two decades, we have witnessed the extensive activities of people with disabilities, resulting in the shaping of a social policy calling for their full integration in society including, amongst others, providing accessibility of services and fulfillment of social rights (including the right to employment), which will enable optimal quality of life for people with disabilities.

At the theoretical level this acknowledgment is manifested in the development of bio-psycho-socio approaches to disability and health definitions. Based on these developments, we have examined a bio-
psycho-social model based on ICF classification (WHO, 2001). This model was used to evaluate the separate and combined contribution of personal, environmental and structural-social factors to explain and predict personal well-being. The research model was tested on two sub-population groups: women with disabilities compared with those with occupational barriers due to socio-economical background. Both participated in joint programs for vocational program aimed at job placement and included 342 young women of working age, living in conditions of economic and social deprivation.

Research findings confirm the person-environment model of well-being, explaining and revealing different relationship patterns between and within the groups. The findings have implication on social policy as well as practice of women with and without disabilities.

4. Darren Lillington, David Shannon (Canada, United Kingdom) 
Queens University, Kingston, Ontario and Faculty of Law, University of Leeds

“Can The UNCRPD Reverse The Denial Of Disability Rights To Aboriginal People In Ontario?”

In the presence of a seemingly strong domestic disability rights regime how can the United Nations Convention on the Rights of Persons with a Disability assist communities that are perpetually denied basic human rights?

The recent signing of the United Nations Convention on the Rights of Persons with a Disability (CRPD), and subsequent ratification by many UN member states, has created a wave of optimism that this may generate a new era of disability rights promotion for the 600 million individuals living with a disability throughout the world. Arguably, there has been much self-congratulations among the governmental and non-governmental parties that participated in the negotiations and drafting of the CRPD. At this juncture, the question of whether the rights and principles articulated in the CRPD will have a meaningful impact on the most vulnerable communities bears close examination.

Ontario is Canada’s largest province and one of the wealthiest jurisdictions in North America. Coinciding with this broad social affluence has been a strong human rights regime within a common law tradition. This has meant socio-economic advancements for many Ontarians living with a disability. The literature indicates that, for a significant portion of this community, the independent living movement has realized its vision of full community participation.

This success has not been visited upon the Aboriginal community of Ontario. The Canadian Paraplegic Association Ontario has undertaken a comprehensive survey and project development to provide client services to meet the social and advocacy needs of Aboriginal persons living with a spinal cord injury. Findings indicate that, although approximately 35% of
the Aboriginal community has a disability, they continue to encounter barriers to primary health care, housing, transportation and other essential services at a far more significant rate than their fellow citizens. This paper will use the jurisdiction of Ontario to ask whether, in light of the fact that a strong existing human rights regime has not been able to advance a successful independent living model for Aboriginal persons with a disability in Ontario, can the United Nations CRPD make any difference? This will be determined by first examining what gaps exist in the legislation and policy as it applies to the Aboriginal disability community in Ontario. Where gaps do exist to attaining basic human services, options for legal redress available to Aboriginal individuals in order to meet the principles articulated in the CRPD will be identified. Finally, it will be discussed how law, policy and services can be improved in order to close the socio-legal gaps experienced by Aboriginal people in Ontario.

5. Darragh McCausland (Ireland)
University College Dublin

“A study of the needs of older adults with Intellectual Disability and its implications for Irish policy”

In the presence of a seemingly strong domestic disability rights regime how can the United Nations Convention on the Rights of Persons with a Disability assist communities that are perpetually denied basic human rights? The recent signing of the United Nations Convention on the Rights of Persons with a Disability (CRPD), and subsequent ratification by many UN member states, has created a wave of optimism that this may generate a new era of disability rights promotion for the 600 million individuals living with a disability throughout the world. Arguably, there has been much self-congratulations among the governmental and non-governmental parties that participated in the negotiations and drafting of the CRPD. At this juncture, the question of whether the rights and principles articulated in the CRPD will have a meaningful impact on the most vulnerable communities bears close examination.

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6. Janet Swinburne  
Ph.d Candidate, School of Nursing & Midwifery, Trinity College Dublin

“Advancing the Inclusion of People with Intellectual Disability in National Research: An Overview of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)”

While ageing in people with intellectual disability is an incredible success story, it is also a tremendous challenge, as we know little about the ageing of people with intellectual disability in Ireland or indeed in any country, and we now have an opportunity to hear their voices and gather critical information. The inclusion of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing represents a major step towards building the evidence on which to base the development of sound policies in areas concerning older people with intellectual disability, and to integrate this population group into future national health and social care policies, and services.

Uniquely, this is the first national longitudinal study on ageing in persons with intellectual disability in Europe, and the only study with the potential of comparing the ageing of people with intellectual disability directly with the general ageing population. The study will involve approximately 800 people with intellectual disability aged 40 years and over from across Ireland, charting their health, social, economic, environmental and psychological status as they age over a 10-year period. The sample for the study was randomly selected from the National Intellectual Disability Database. The resulting sample will aim to represent the appropriate urban/rural mix as well as age, level of intellectual disability, residential circumstance and geographical regions across Ireland.

Participation in the study is voluntary. Fieldwork involves the administration of a pre-interview questionnaire followed by interviews in the participants’ home using a computer aided personal interviewing (CAPI) programme, where appropriate, or a pen-and-paper questionnaire. Participants will be visited three times over a ten year period. The first wave of the study commenced in November 2009. Baseline data will be
collected for one year, and data cleaning, analysis and report writing will commence thereafter.

Close harmonisation between the Intellectual Disability Supplement and TILDA will ensure that the differences and similarities between the population groups nationally are systematically ascertained, so that future policies, services and resources meet the needs of both respective groups as they age in Ireland. The development of rigorous protocol guidelines ensure the Intellectual Disability Supplement is closely aligned with The Irish Longitudinal Study on Ageing (TILDA), which in turn is closely harmonised with the English Longitudinal Study on Ageing (ELSA), the Study of Health and Retirement in Europe (SHARE) and the US Health Retirement Study (HRS). The value of internationally comparable longitudinal data is widely recognized and Ireland has positioned itself to become a leader in cutting edge longitudinal ageing research in persons with intellectual disability, and its potential to undertake comparative analyses with the general ageing population. The Intellectual Disability Supplement to TILDA is being carried out by Trinity College Dublin under the leadership of Principal Investigator, Prof. Mary McCarron. The study is funded by the Health Research Board and the Department of Health and Children, through the Office of the Minister for Equality, Disability and Mental Health.

G: Employment Law & Policy

Chair: Dr. Barbara Murray (Senior Disability Specialist, International Labour Organization)

1. Claire Bruton BL (Ireland)
   Ph.d Fellow, Centre for Disability Law & Policy, NUI Galway

   “The relationship between reasonable accommodation and non-discrimination-has Ireland got it wrong?”

Reasonable accommodation as a concept induces employers to re-examine norms of the predominant society without which historic discrimination and inequality of opportunity for individuals with disabilities is merely perpetuated. It recognizes that the disabled person and the non disabled person do not reach equality in a similar manner and thus some form of accommodation is required. In the employment sphere, it requires employers to remove barriers and make adjustments to the work environment or structure, in order that disabled individuals are placed in a similar position to their non-disabled counterparts. It requires employers to generally take a proactive approach to locating suitable measures with which an individual with a disability can be accommodated in the workplace. In this regard it requires an individualized approach by employers. It allows adjustments to be made in order that disabled employees may be deemed capable of performing the essential tasks of a particular job, but if the individual cannot do so with the aid of reasonable
adjustments or if the adjustments are simply too expensive for the employer, then the requirement is not necessary.

This paper will critically examine the legislative framework of reasonable accommodation in Irish law. This paper will analyze the Irish legal framework around reasonable accommodation and whether failure to provide same will amount to a standalone cause of action by way of a finding of discrimination as against an employer/prospective employer or as a form of direct or indirect discrimination. After determining the issue from an Irish perspective, the paper will engage in a comparative legal methodology of other jurisdictions which considers whether an employer’s unjustifiable refusal to engage in the proactive duty to consider reasonable accommodation and or failure to provide same is regarded as direct or indirect discrimination or both or a unique and distinct form of discrimination. In light of this analysis, the paper will determine whether the Irish approach is correct in particular in light of the requirements imposed by the Framework Directive. Moreover the paper seeks to determine whether a consensus on the issue of the relationship of reasonable accommodation and non-discrimination can be established from the comparative research.

Given the large proportion of litigation concerning employment and disability which involve reasonable accommodation simpliciter, the issue is of significant importance in this jurisdiction. Indeed, the status of reasonable accommodation in the disability non-discrimination framework may well determine the effectiveness of combating discrimination on grounds of disability. The paper concludes on the practical and academic ramifications on the issue of whether, and if so, in the manner which in which the failure to provide reasonable accommodation fits into the non-discrimination landscape.

2. Gemma Carney and Camille Loftus (Ireland)
Irish Centre for Social Gerontology, NUI Galway and University College Dublin

"Linking Civic Participation and Economic Independence: Institutional structures and employment policies for people with disabilities in the Republic of Ireland”

This paper emerges from a larger project comparing third sector lobbies in the Republic of Ireland. The project is concerned with how different vulnerable groups are represented in decision-making processes. Children, people of working age and older people are identified as having distinct needs according to their life stage. People with disabilities are recognized as needing appropriate supports to be independent throughout the lifecycle. The establishment of this ‘lifecycle’ approach to policy-making emerges from international proposals for reform of social policy-making in response to demographic ageing (OECD 2007). In the Irish system, each group is referred to as a ‘stage’ in social partnership negotiations, the national system of collective bargaining. Vulnerable groups are represented by member organizations of the Community and Voluntary
Pillar (CVP) in this system. The current paper focuses on the achievements of the disability lobby, linking those gains to economic independence for people with disabilities.

The disability lobby has achieved a legislative base culminating in the Disability Act, 2005, with supporting institutional structures. The United Nations Convention on the Rights of Persons with Disabilities and the newly published European Commission draft Directive on discrimination are set to become significant drivers of change. The governance framework arising from these policy initiatives established key goals across a spectrum of issues from health to welfare and employment. There are many potential impacts of this institutional change. However, the specific focus of this paper is to question the impact of this institutional change in terms of its potential to yield concrete improvements in the economic independence of people with disabilities. This paper takes a detailed look at the governance framework and institutional structure for people with disabilities in Ireland, linking the civic participation of people with disabilities in social partnership to levels of economic independence at the individual level.

Within the Irish social welfare system, disability is effectively defined as an inability to work (temporary or permanent). A key question for disability specific institutions then is the extent to which they integrate/engage in their work with key mainstream institutions concerned with economic independence e.g. social welfare systems, education and training services, and broader labour market services. This paper will explore the role that disability representative organisations are playing in this process. Do they engage with the Department of Social and Family Affairs in relation to the development of a capacity assessment on disability payments? What role do lobbies play in the development and monitoring of pilot projects at the local level? How do they engage with social partnership groups focused on the labour market, education and training? In examining this issue the paper contributes to an international literature concerned with disability and inequality in diverse national contexts.

3. Xiao Junyong, Wang Jing, Chen Jiali (China) (unable to attend)
University of International Relations

“Employment Status and Legal Protection of Persons with Disabilities in China”

The right to employment of persons with disabilities means that the disabled with working capacity shall have access to work and receive remuneration in accordance with the quality and quantity of the work, enjoy the labor safety and hygiene, obtain vocational training, entitle to social security as well as special aid, preferential treatment and protection. It’s mainly through employment that persons with disabilities can improve their living standard, participate in social life and achieve their values of life.
Our Government is always placing great emphasis on the employment of the disabled and accelerating the pace to perfect the legal protection system for it. Up till now, a Constitution-centered legal framework that not only meets the needs of the market economy but also protects the disabled’s right to employment has been established. China has developed an employment mode mainly led by governmental arrangement and supplemented with social participation and pro-rata employment and has adhered to the policy of combining concentrative placement with scattered employment through multi-channel, multi-level and multi-form arrangements.

In recent years, the employment rate, scale and services of the disabled in China have made great achievements, but against the backdrop of the overall severe situations for employment, as for the most disadvantaged group—the disabled people, problems such as the low level of employment, low income, unbalanced development, etc. cannot be neglected.

This essay will start with the difficulties in employment encountered by the disabled in China and make an analysis of the reasons for that. In order to allow the disabled to share the benefits brought by the economic and social development, legal protection becomes the most effective means to achieve their right to employment. Therefore, on the basis of the difficulties faced by the disabled in China, this essay will come forward with some legal measures to protect their right to employment, suggesting the Government to take a series of effective steps to strongly promote the comprehensive employment of persons with disabilities.

4. Ruth Tindley (United Kingdom)
University of Leicester

“Assessment of Incapacity for Work for People with Mental Health Problems: Is it Justiciable?”

The UK social security system distinguishes between “disability” and “incapacity for work”. It provides for a disability benefit which is intended to meet the extra costs of disability, and a benefit for people with limited capability for work, which is designed to replace earnings. It is possible for a person to receive either, or both these benefits. In October 2008, significant changes were made to the benefits paid for incapacity, and my research is looking at how people with long-term mental health conditions are affected by the system.

A major difficulty is that of sorting out who can and cannot work, and at what stage it becomes unreasonable to expect a person who is sick or disabled either to have to work or to prepare themselves for employment. As part of my research I am looking at the various methods of assessment that are used to decide whether a person is able to work or not. Assessment of incapacity for work is particularly problematic when the cause of incapacity is mental rather physical illness or disability. Methods of assessment that may be used are:
• informal methods
• Barema methods
• determination of functional capacity
• estimation of economic loss
• assessment of care needs

The presentation will consider the advantages and disadvantages of each of these methods, and then outlines the assessment process used in the UK. It concludes with a discussion as to whether it is possible for a social security system to determine the capacity for work of a person with mental health problems.

5. Susan Barak (Canada)
PhD Candidate, York University, Toronto

“Of Tort and Trauma: The Vital Nature of Legal Remedies to Address and Redress Disability Harassment in the Workplace, with a Focus on Ontario”

The phrase “disability harassment” may be relatively new, but the experience of harassment for disabled people in the workplace is a long-standing problem (Ravaud & Stiker, 2001). Employment may often be a key factor in affording significant contributions to an individual’s health and wellbeing, as well as their ability to reach their potential to contribute to society, thus it behooves us to be apprised of potential pitfalls related to accommodation, discrimination, and harassment, since these often work in lockstep in the course of a disabled person’s employment-related experience (Malhotra, 2006).

The need to recognize and respond to the rampant problem of violence at work in general is demanded increasingly internationally. The conspicuous confluence of social and economic forces in dramatic flux must be capitalized on to achieve tangible gains in actualizing the vision of respect for all in a fair and inclusive workplace environment, in concert with our Canadian Charter, with dignity as its lodestar (Shannon, 2007). It is my position that we cannot let our comparative successes lull us into a relative complacency and allow advocacy and advances to flag.

This presentation identifies where there are issues, possible remedies, problematic gaps, and a look to other jurisdictions for possible avenues of action to pursue with a view to enhancing the protection and enforcement of the rights of disabled people in the Ontario labour force and workforce. I will argue that the cost of disability harassment to individuals, coworkers, organizations, and society is too significant in magnitude as well as scope to be permitted to continue without enlisting the maximum available resources and remedies, to heal where there has been damage, and deter further harm. I will also analyze the limits of legal remedies to halt and heal the tandem scourge of disability discrimination and harassment in the workplace.
**H: Mental Health Law & Disability**

**Chair:** Dr. Mary Keys (Lecturer in Law, School of Law, NUI Galway)

1. **Phil Fennell (United Kingdom)**
   Professor of Law, School of Law, University of Cardiff

   “Disability Rights and Mental Disorder”

   This paper considers the impact of the UN Convention on the Rights of Persons with Disabilities on the rights of people who suffer from mental disorder. The paper focuses on two issues. First the entitlements of mentally disordered people to independent living, and second the extent to which it may be contrary to the Convention for states to maintain legislation authorizing detention on grounds of mental disorder.

2. **Vaneesha Jain, Deepaloke Chatterjee (India)**
   West Bengal National University of Juridical sciences, Kolkata, India

   “Between Legal Romanticism and the Rule of Law - Reviewing the ‘Insanity Defence’ of the Indian Penal Code in light of the equal capacity approach proposed by the UNCRPD”

   The interface between Indian domestic law and India’s international obligations has always been a problematic area for the Indian legal system given the remarkably opposite aims and ambitions of each. On the one hand, India has been attempting to become a superpower in the international legal order and yet, a significant portion of her population struggles daily with problems relating to food, housing and clothing. India is a party to the UNCRPD. This Convention recognises equal capacity and uses the rights approach. Equal legal capacity is the most revolutionary of the new norms encompassed by the CRPD, and it places an emphasis on the mental state of mind rather than any physical capacity. This in turn ensures that India must harmonize its domestic law to be in conformity with her international legal obligations.

   Municipal legislation(s) in India recognise inequality of capacity for persons with disability, in particular mental disability, e.g. with reference to competence to contract or to hold property, which are limited or excluded in case of persons ‘unsound of mind’. In addition, the Indian Penal Code, 1860 [“IPC”] re-emphasises the inequality of capacity and even creates the ‘insanity defence’, and grants total exemption from criminal liability to persons suffering from unsoundness of mind. (These rules are commonly referred to as the M’Naghten Rules).

   In some areas of criminal law in India, there is a call for shift in approach from being accused centric to victim centric, e.g., in rape laws, the judicial
system today tries to be centred on the trauma caused to the victim rather than providing cushions in terms of legal provisions in favour of the accused. The approach is also reflected in the emerging regimes of no-fault liability including strict liability and absolute liability which are being increasingly applied to environmental and tortuous matters. In these new approaches, primary importance is given to correcting the harm done to the sufferer rather than punishing (or protecting) the offender. Thus it is a shift to a more corrective approach to equality. The application of such principles in terms of criminal actions by a person suffering from unsoundness of mind would mean doing away with the defence provided for in the IPC.

As is obvious, there is a basic conceptual difference in the equal capacity approach of the CRPD and the inequality of capacity-based exemption from liability approach of the IPC. However, the harmonization of these apparently conflicting concepts will soon become fundamental for the proper governance of the polity. This necessitates a definite demarcation of these two concepts, while giving due regard to each. The final presentation and paper will be an attempt by the authors to identify the issues surrounding the differences in approach of the CRPD and the IPC including the merits and drawbacks of both the approaches, as well as the basic doctrine of mens rea underlying criminal law in India, in order to attempt a resolution of the two approaches to bring them in harmony with each other.

3. Suzanne Doyle (Ireland)
Ph.d Candidate, University College Cork

“Does the UN Convention on the Rights of Persons with Disabilities permit the Involuntary Detention of Persons with Mental Illnesses?”

Article 14 of the CRPD states that:

1. States Parties shall ensure that persons with disabilities, on an equal basis with others:

(a) Enjoy the right to liberty and security of person;
(b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty...

Prior to the entrance into force of the Convention, the existence of a mental disability represented a lawful ground for deprivation of liberty and detention under international human rights law (For example, the UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (A/RES/46/119). At a regional level, article 5(1)(e) of the ECHR also permits the deprivation of liberty of "a person of unsound mind" where it is "prescribed by law".).
Proposals made during the drafting of the CRPD to limit the prohibition of detention to cases “solely” determined by disability were rejected. Therefore ‘unlawful detention’ under the CRPD even encompasses situations where the deprivation of liberty is grounded in the combination between a mental or intellectual disability and other elements such as dangerousness, or the need for care and treatment. Since such measures are partly justified by the person’s disability, it would appear that they are to be considered discriminatory and in violation of the prohibition of deprivation of liberty on the grounds of disability contained in Article 14.

The UN High Commissioner for Human Rights has suggested that Article 14 of the CRPD should not be interpreted to mean that persons with disabilities cannot be lawfully subject to detention for care and treatment or to preventive detention, but that the legal grounds upon which restriction of liberty is determined must be de-linked from the disability and neutrally defined so as to apply to all persons on an equal basis.

This paper will seek to explore what alternative legislative and theoretical models might be utilised by States Parties to the CRPD to justify the compulsory detention of persons with mental illnesses in such a ‘disability-neutral’ manner and, more fundamentally, whether this is actually achievable.

4. Liz Brosnan (Ireland)  
University of Limerick

“Why We Need To Learn Legalese: Human Rights Based Approach and the Principle of Mental Health Service User Involvement”

The Human Rights Based Approach to mental health service user involvement uses the human rights frameworks to exercise the right to health: set out in Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESR). This right to health contains the freedom to make decisions about one’s own health; the entitlement to a system of health protection; available, accessible, acceptable health facilities, goods and services that are appropriate and of good quality; non-discrimination; government obligations to respect, protect and fulfil the right to health; monitoring; accountability mechanisms and remedies; and finally, participation. The Convention on the Rights of Persons with Disabilities (CRPD) reinforces the principle of participation and the importance of service user/rights holder involvement more generally. So, for example, Article 4(3) states:

"In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations."
The principle of participation is therefore a key component of the Human Rights Based Approach to health, including Mental Health, and permeates all of the above aspects of enjoyment of the right to the highest attainable standard of health. The principle of participation is the focus of this paper. There are two elements to this principle:

- participation in individual care and treatment planning; and
- participation in developing, implementing and monitoring law, policy, programmes and services.

As the Irish State is the principle duty bearer of this right to health and the primary provider of mental health services in Ireland, there is a particular responsibility on the State to develop mechanisms to facilitate participation. Previous empirical research by this scholar indicated a major deficit in terms of partnership working in mental health services in the west of Ireland, with wide-spread failures to communicate clearly with service users or to consult with people about their care and treatment. Partnership was conceptualised under two categories: Therapeutic partnerships, which are closely aligned to the first type of participation, at the individual level of care and treatment: secondly, Strategic partnerships which can be aligned to the second form of participation outlined above; that of the involvement of service users in planning, delivering and monitoring policy and services. Failures of partnerships with service users at both levels suggest that much work is required to understand and realise the principles of participation, and of human rights frameworks.

A Human Rights Based Approach can become a powerful mechanism to leverage movement on the right to participation at all levels on decisions affecting care and treatment, but also at strategic levels of service development, monitoring, evaluation as well as policy development. How a Human Rights Based Approach to user involvement might be understood and utilised by mental health service users as rights holders will be explored in some detail in this paper.

5. Charles O'Mahony (Ireland)
   Ph.d Fellow, Centre for Disability Law & Policy, NUI Galway

   “Mental Illness and the Criminal Justice System”

This paper examines the interaction between mentally ill persons and the criminal justice system. The relevant Irish law and policy will be critically examined and the challenges and the shortcomings with the current system will be set out. The lack of community psychiatric services and other social services will be considered as contributing to the increasing criminalization of mentally ill persons. Effective methods for diverting mentally disordered offenders out of the criminal justice system will be discussed by way of comparative analysis. Law and policy in North America, New Zealand and Ireland will be considered.
This paper examines the impact of the Mental Health Act 2001 on patients under the age of 18. The Mental Health Act 2001 has been in force since the 21st November 2006. The Act signalled a new era of mental health law in Ireland, establishing a framework for mental health services which would respect human rights and ensure independent and regular review of detention of people who suffer from a mental disorder. Despite the impetus for change, children and adolescents have, however, been largely overlooked in the reform of mental health legislation.

This paper will discuss current provision for children under the 2001 Act, focusing on admission and the system of review. Admission under the 2001 Act is based on the categories of voluntary and involuntary admission. Only patients suffering from a mental disorder can be detained as involuntary patients. The definitions and categories of mental disorder, and voluntary and involuntary admission, are applied to both children and adults. There are however significant differences in the practical application of these terms depending on whether or not the patient is over 18 years of age. The majority of children and adolescents requiring in-patient treatment are admitted at the request of their parents, as voluntary patients. The Law Reform Commission has recently addressed this issue, noting with concern that the process of involuntary admission, under section 25 of the Mental Health Act, can be circumvented by obtaining parental consent to admit a child as a voluntary patient. Where the distinction between a voluntary and an involuntary patient is blurred in such a way, it is doubtful if appropriate safeguards can be applied. Incorrect categorisation as a voluntary or involuntary patient may also have implications for the type of treatment that a patient receives. The term voluntary is not an accurate description of a patient who has not given consent for his or her admission, cannot consent to treatment and cannot leave the centre. Furthermore, children who are detained as voluntary patients do not have the protections and safeguards granted to children detained as involuntary patients, such as review of their admission.

The practice of admitting a child ‘voluntarily’ on the basis of parental consent has been criticised and is out of line with children’s rights principles. The European Court of Human Rights addressed the issue in 2005. In 2007, significant amendments to mental health legislation were made in England, in order to end the informal admission of adolescents on the basis of parental consent. This paper analyses these developments and advocates reform of the Mental Health Act 2001 to ensure that the rights of all patients are respected, including those below 18 years of age.
I: The Right to Inclusive Education (1)

Chair: Dr. Andrew Power (Centre for Disability Law & Policy, NUI, Galway)

1. Bronagh Byrne (United Kingdom)
   Queens University Belfast

   “Snakes and Ladders or New Beginnings? Assessing the effectiveness of the UNCRPD in protecting the equality rights of children with disabilities”

The concepts of equality and non-discrimination have long occupied a central position in international human rights law. Despite widespread guarantees of equality and non-discrimination in the Universal Declaration on Human Rights and ensuing treaties, the precise meaning and scope of these concepts have been a source of contention since only a few human rights instruments have expressly provided for a definition of ‘distinction’ or ‘non-discrimination’.

Children with disabilities are theoretically protected by core human rights treaties such as the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Political Rights (ICESCR). However, “merely because an international instrument is capable of being applied to children does not mean that it incorporates a coherent child-centred approach setting out all the rights necessary to ensure the basic dignity of children”. Nor has it been evident from these core treaties how traditional human rights values such as equality and non-discrimination are to be interpreted and applied to the specific experiences of a group experiencing both additive and intersectional forms of discrimination. The textual invisibility of multiple grounds for discrimination, and of children with disabilities more specifically, in mainstream human rights law has embedded the invisibility of this particular group within the human rights paradigm; itself based on ‘able-bodied’, adult norms, reinforcing processes of ‘othering’.

This paper will explore the extent to which the UN Convention on the Rights of Persons with Disabilities (2006) denotes a meaningful window of opportunity in asserting and progressing the equality rights of children with disabilities. Both the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities are undoubtedly major steps forward in protecting the equality rights of children with disabilities. The increasing attention paid by the Committee on the Rights of the Child to disability issues in general comments and in concluding observations of States Parties must not be dismissed. However, the CRC text is arguably secondary to the CRPD in addressing the ways in which the concepts of disability and equality apply to the discourses of each other. That the CRPD begins from a social model of
disability in contrast to the welfarist approach adopted by the CRC is a further illumination.

It remains to be seen how the CRPD’s provisions will be interpreted by its Committee and implemented by States Parties. However, lest the CRPD becomes reminiscent of a game of snakes and ladders, it is vital that explicit attention is paid to the lived experiences of children with disabilities from the outset; both in the work of the Committee and in the implementation and monitoring mechanisms established by States Parties under Article 33.

2. Joyce Mortimer (Ireland)
   Ph.d Fellow, Centre for Disability Law & Policy, NUI Galway

   “Inclusive Education – Beyond Ideology”


These laws, however, have been met with considerable opposition. Inclusion is opposed on the basis that special or pull-out classes remain the most appropriate means of educating children with disabilities. Inclusion is seen as grounded in ideology, having no evidence of its effectiveness in practice. This paper will argue that inclusive education is more than an ideological concept. This argument will be based on the two following main points:

- Disabilities have been defined, re-defined and re-named continuously throughout history in accordance with socially held opinions. This, in turn, has had a direct effect on the type and standard of education provided to children with disabilities. The eugenic movement involved segregation and institutionalisation. The medical model of disability influenced the creation of special education and pull-out classes. The social model of disability has forced a review of segregationist policies and a move towards inclusive education.

- Special education is a practice which has evolved over many centuries in response to a variety of societal factors. Special education is not an inherent aspect of schooling. It is based on concepts of standardisation, labeling and classification. It is a practice that both strives and ensures to keep an oppressed group oppressed. Those opposing inclusive education call for evidence of its effectiveness in advance of its implementation whilst ignoring the proven failures and shortcomings of the existing segregated system. Stereotypical, prejudicial beliefs inform the special education argument. Segregated education mirrors the
discriminatory stratifications existent in society. Inclusive education, on the other hand, is based on principles of equality, non-discrimination, autonomy and independence.

It is argued here that inclusion is a realistic option and, more fundamentally, the only option conforming with International Human Rights standards. The practical implementation of inclusive education requires the admission of children with disabilities into local mainstream schools. Services should be provided based on need rather than labels, and should be available to all children, those with disabilities and those without. Supports and accommodations should be provided in the regular classroom. Curriculum must be reformed to respond to pupil diversity.

Inclusive education is based on the following general principles:

- Human diversity is inevitable and natural. It is futile to use a ‘norm’ as a comparator against which all people are to be assessed.
- Common human characteristics transverse the socially constructed delineations of gender, race, disability, class, and sexual orientation.
- Diversity and varying educational competency is to be expected in any classroom. Learning is possible and even enhanced in an inclusive setting.
- Inclusive schooling fosters equality in encouraging a sense of community and co-operation. The fundamental tenet of inclusive education is the welfare of all students.

3. Elizabeth S. Mathews (Ireland)
NIRSA, NUI Maynooth

“Mainstreaming of Deaf Education in Ireland”

A great deal of educational policy in recent years has identified the local public school as the favoured location for the education of children with special educational needs (for example in the US PL 94-142 which became the Individuals with Disabilities Education Act; in the UK the Education Act 1981, and in Ireland the Education Act 2000 and Education for Persons with Special Educational Needs Act 2004). The inspiration for much of the Irish legislation came from the Salamanca Statement of 1994, which promotes the inclusion of children with disabilities in mainstream schools. However, the Salamanca Statement also specifies that the case of deaf children may be a notable exception to this rule, where segregated schooling may be the more appropriate and indeed inclusive option. In spite of this, it is estimated that 90% of deaf children are in mainstream settings in the Irish context.

This paper will examine why it is that deaf children are an exception to the mainstreaming agenda, and why it is that in spite of this, mainstreaming has become almost hegemonic as an educational approach. Supported by findings from research with hearing parents of deaf children in Ireland, it will argue that the mainstreaming of deaf
children is not so much a case of inclusion, but rather a process of medicalization and normalisation.

4. Sheelah Flatman Watson (Ireland)
NDA Scholar/NIRSA Affiliate, Department of Geography, NUI Maynooth

"Implementation of equitable enrolment processes and equality of opportunity in primary education environments: the case of pupils with a diagnosis of an intellectual and/or a pervasive developmental disability"

It was recognised that 'a great number of citizens are excluded from the rights and opportunities of the vast majority' due to societies being 'organised for an “average” citizen without any disability' and in particular that 'some young people continue to have problems of access to mainstream education...' (European Union, 1996). Member states were called upon to provide integrated educational environments with support services (European Union, 2003). The UN Convention on the Rights of Persons with Disabilities requires States Parties to ‘ensure an inclusive education system...’ and that ‘persons with disabilities are not excluded from the general education system on the basis of disability, (United Nations, 2006, Article 24). National statutory instruments are enacted that promote equality and inclusion, with support as required. However, systemic adoption and societal accommodation these policy developments are far less definitive.

This paper argues that a transition from historical practices of segregation to accessibility of mainstream education environment is impeded by the lack of States commitment to the provision of pertinent resources and structures to effect universal enrolments on an equitable basis. Drawing on research located across two counties in Ireland, Dublin and Kildare, which encompassed three phases including 1) a Schools’ Survey (245) of special education provision, 2) a Parents’ survey (119) of experiences of accessing the system and 3) 30 semi-structured/narrative interviews with a stratified sample of parents, it is argued that discriminatory practices enshrined in the organisation of the Irish Education system deny equality of access to mainstream education environments. The lack of capacity at multiple levels of the system to facilitate the needs of pupils with ID/ denial choice of primary educational placement for 54% of the children (Flatman Watson, 2009). The paper offers recommendations to enhance more equitable enrolment practices and the potential for equality of opportunity in inclusive educational environments. The resource sensitivities that mediate access to placements is rarely, if ever, considered. This paper, addresses this lacuna.
I: The Right to Inclusive Education (2)

Chair: Senator Fidelma Healy-Eames

1. Jean Daly, Clare Daly (Ireland)
University College Dublin, Irish Wheelchair Association, Disability Sport Northern Ireland and University College Cork

"Who gets to play?- An Examination of the Inclusivity of Physical Education in Primary School Education in Ireland with a Focus on Children with Physical Disabilities”

Physical Education has been identified as an essential component to the complete education of a child, yet there is a marked failure to provide for the inclusive education of children with a physical disability in mainstream P.E. classes. NCCA guidelines recognise P.E. as an “integral part of the total curriculum” which “provides vital opportunities for the physical, social, emotional and intellectual development of the child.” Further, the promise of an inclusive education system has been lingering in Ireland for a number of years. International and national legislation provides the theoretical ideals of inclusion, support and equality for all children in the primary school system from the UNESCO’s Salamanca Statement in 1994 to the United Nations ‘Convention on the Rights of Persons with Disabilities, 2006, to the Irish Constitution, the Education Act 1998 and the Education for Persons with Special Educational Needs 2004, amongst others. The ethos of inclusion and equality underpins education law and provides a clear direction to schools that students are to be educated together, in inclusive classes, irrespective of ability.

The definition of ‘special educational needs’ in Irish legislation has incorporated a wide range of disabilities, including physical disability. However, it appears that the focus is on providing SEN support only in academic subjects and exclusively for children with intellectual disabilities. Para 3.1.5 of the NCCA Special Educational Needs: Curriculum (1999) states that the focus of physical education will be on students with cognitive difficulties and no policy would be put in place for students with physical disabilities “at that time”. Unfortunately, some eleven years later, the NCCA has yet to implement a policy for students with physical disability to take part in PE.

In addition, the Primary School Physical Education Curriculum (1999) provides just one line in respect of the physical education of children with special needs: ‘(T)he class teacher encourages maximum participation in the physical education lesson by the child and provides the opportunity to benefit from a balanced physical education programme”. While more recently, the Special Educational Needs: A Continuum of Support Guidelines for Teachers, 2007, fails to mention physical education in the entirety of the document.
The writer identifies four areas that require change in order to maximise the inclusion of children with physical disabilities in P.E. in Ireland: physical, instructional, social and organisational inclusion. Further, lessons can be learned for example from the USA which is the only country with a recognised law mandating P.E. for students with disabilities. From a practical perspective, the writer has assisted in promoting this ideal of inclusive P.E. classes to both schools and the national teacher training college. While attending primary schools for training purposes, it became clear that Ireland is failing to provide a full education to children with a physical disability. Further, there is a notable absence of teacher training on a national level to promote inclusive P.E. classes. This paper seeks to present a legal and policy analysis of this failure and will incorporate the practical experiences on the writer whilst working with the IWA in primary schools.

2. Shivaun Quinlivan (Ireland)
   Lecturer, School of Law, NUI Galway
   “The efficacy of public interest litigation with regard to the right to education for children with disabilities”

3. Paul Emong (United Kingdom)
   School of Law, University of Leeds
   “Implementation, Impact and Further Development of the Ugandan Disability Law at Higher Education”

This paper draws on the finding of my ongoing PhD work: “an investigation into the realisation of human rights for disabled people in higher education in Uganda through disability legislation.” Which concludes that despite Uganda having a wide scope of legal provision on disability inclusion and it being woven into the fabric of the national legal framework, the experiences of disabled students in the institution of higher education point out that the disability legislation has not penetrated higher education enough to bring about effective disability policy changes to both academic and non-academic programmes. Thus, this paper serves three purposes in respect to the disability legislation and inclusion of disabled people in higher education. One, it critically examines how the law has been implemented. Two, it provides its current impact at higher education. Three, it proposes and examines areas for further development of the disability legislation to make it an effective law in higher education in-line with the requirements of international human rights law, using UK approach as a case study.
4. Breda Casey, Edel Tierney  
NUI Galway, National Federation of Voluntary Bodies  
Providing Services to Persons with Intellectual Disability

“Supporting civic engagement of persons with  
intellectual disabilities through access to inclusive 3rd  
level education”

The aim is to develop a partnership pilot project to support the civic engagement of persons with intellectual disability disabilities through access to 3rd level education at NUI Galway. NUI Galway has a specific commitment to embrace community and civic engagement as part of its core mission and is committed to offering a “holistic educational and cultural experience to its diverse student body” (NUIG Strategic Plan 2009-2014). The Strategic Plan of the UNESCO Chair in Children, Youth and Civic Engagement strongly reiterates this commitment and under Strategic Goal No. 2 provides for collaboration between the UNESCO Chair, the Community Knowledge Initiative (CKI), and the National Federation of Voluntary Bodies to include persons with intellectual disabilities in third level education at NUI Galway, guided by UNESCO’s guidelines on inclusive education (UNESCO Chair Strategic Plan 2010-2013).

These commitments align with Article 24 (5) of the UN Convention on the Rights of Persons with Disabilities which outlines that persons with disabilities have a right to “… access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others” (United Nations, 2006). Traditionally the route for persons with intellectual disabilities leaving second level education in Ireland is entry to rehabilitative training, vocational training/employment, supported employment or sheltered workshops and day services. The demand for third level opportunities for persons with intellectual disabilities exceeds availability with few opportunities available to students in the West of Ireland.

Professor Pat Dolan, UNESCO Chair in Youth and Civic Engagement, and Director, Child and Family Research Centre; Professor Gerard Quinn, Director, Centre for Disability Law & Policy; and Ms. Edel Tierney, Director of Research & Policy Development, National Federation of Voluntary Bodies will lead the pilot project in NUI Galway. Capacity to drive the project forward and to develop the proposed pilot project will be provided by NUI Galway and will be supported by a steering group comprised of all stakeholders. A core principle of the pilot is to provide an opportunity for persons with intellectual disabilities and families to give their views and opinions. Ten focus groups with persons with intellectual disabilities and six focus groups with parents and families have now taken place. The knowledge gained from these focus groups will be crucial to the development and rollout of a pilot that meets the needs of the students with intellectual disabilities. In developing this initiative it is anticipated that NUI Galway will collaborate with other national and international higher education institutions in Ireland and internationally (e.g. Canada)
that provide opportunities at 3rd level for students with intellectual disabilities.

5. Niamh Lally, Tomas Murphy, Molly O’Keeffe, Mai Lin Yap
   National Institute for Intellectual Disability (NIID), Trinity College, Dublin
   “Breaking Boundaries: The Experiences of Students with Intellectual Disabilities in Inclusive Third Level Education in Ireland”

The United Nations Convention for the Rights of Persons with Disabilities (2006) specifies that all persons with disabilities have the right to an inclusive education system at all levels. Specifically, Article 24 on Education challenges post school education providers to ensure that ‘effective individualised support measures are provided in environments that maximise academic and social development, consistent with the goals of full inclusion’ (United Nations, 2006, Article 24, para 2e). Whilst increasingly students with intellectual disabilities are receiving an inclusive education in early childhood, primary and secondary educational settings they are still under-represented in third level or tertiary settings. Enrolments of students with disabilities in post-secondary settings are still considerably lower than enrolment amongst the general population (Wehman, 2001).

Aligned with the philosophy of equal educational opportunity for people with intellectual disabilities the National Institute for Intellectual Disability (NIID), Trinity College, Dublin developed in 2005 the Certificate in Contemporary Living (CCL) the first full time certificate programme for students with an intellectual disability in Ireland. The aim of the CCL is to facilitate lifelong learning for students with intellectual disabilities, develop skills for independent living and promote the full inclusion of people with intellectual disabilities in Irish society. The Certificate is a two year fulltime programme with 36 students enrolled across two cohorts and a further two cohorts of 42 students having graduated from Trinity College. A study on the outcomes for the first cohort of students to undertake the CCL in 2006 – 2008 reported increased student confidence, enhanced self esteem, enlarged friendship networks, independence and positive expectations for the future including viable work options as a result of their participation on the course (National Disability Authority, 2008).

Given the successful outcomes of the CCL it is currently being transferred from Trinity College Dublin to three other third level institutions in Ireland. By working to increase the number of third levels introducing the Certificate in Contemporary Living, the NIID have ensured that a further 50 students with intellectual disabilities are now enrolled in third level education throughout Ireland for the first time. A current study on this rollout of the CCL is being conducted and major findings to emerge include a deepening of students abilities to claim their rights, become catalysts for disability awareness, advocate for college infrastructure change, experience different modes of learning, as well as increased confidence in being able to work in a group and as a member of a team. The study demonstrated that students with intellectual disabilities can be
successfully included in third level environments in line with the outcomes intended with the UN Convention. The discussion will focus on the implications that inclusion in third level education have for people with intellectual disabilities from their own perspective, and the challenges for the implementation of the UN Convention at a national level.

**J: Regional & Comparative Disability Law (1)**

**Chair:** Professor Patricia Noonan Walsh (Adjunct Professor Centre for Disability Law and Policy, NUI Galway)

1. **European Union:** David Hosking
   University of Leicester
   “The UN Convention on the Rights of People with Disabilities and the European Union”

The United Nations Convention on the Rights of Persons with Disabilities is the first international human rights treaty that the European Union has ratified in its own name, and which is legally binding on the EU itself. This paper explores, through a critical disability theory lens, some of the ways in which the Convention may impact EU law and policy in 3 subject areas – non-discrimination legislation, transport policy and the European Social Fund.

The EU adopted the Employment Equality Directive some 10 years ago to prohibit discrimination because of, among other grounds, disability. The Commission has proposed a new directive prohibiting discrimination in the provision of goods and services. Arguably the Convention’s provisions requiring States Parties to prohibit discrimination on the basis of disability are met by the existing and proposed non-discrimination directives. However, while this EU legislation may meet a narrow legal interpretation of the Convention’s requirements, a strong argument can be made that the specific non-discrimination references need to be read in light of the entire Convention, in order to give effect to the general principles of the Convention which provide a broad vision of social inclusion for disabled people. The directives have a number of weaknesses which make them vulnerable to challenge based on the Convention.

The Convention requires States Parties to ‘take appropriate measures’ to ensure that disabled people have access to transportation. The measures are to include the identification and elimination of barriers to accessibility. EU transport policy includes many streams relevant to the progressive realization of these rights. The paper considers ways in which the Convention may influence EU policy in this area of concurrent competencies. Two examples are the mainstreaming of disability in directives such as those imposing harmonised design standards, which include specifications for accessibility, and disability specific provisions such as the regulation on air travel by disabled people. The EU’s transport
policy includes measures which fit traditional notions of judiciable rights as well as measures which fit evolving new governance procedures. The role of the Convention is quite different in these two policy arenas.

The Convention contains a wide range of provisions related to the right to work. The EU’s European Social Fund is targeted at improving employment opportunities for unemployed and socially excluded groups. Disability has been mainstreamed into this programme – that is, in considering which projects should be funded, how the needs of disabled people are taken into account is supposed to be a regular part of the project proposal assessment process. The Convention’s contribution in this area is less as a legally binding treaty capable of supporting judicially enforced rights than as a powerful political influence on both the content of the proposals submitted by the Member States and the assessment of their relative merits.

2. **Africa**: Benyam D. Mezmur
   Community Law Centre, University of the Western Cape


   The global decade (UN decade 1983 - 1992) did not bring about any noticeable improvement in the quality of life of people with disabilities in Africa. Subsequently the period from December 2000 to 2009 was declared by the African Union’s (AU) predecessor, the Organization of African Unity (OAU) in its Thirty-Sixth Session as the African decade for persons with disabilities. Despite this, persons with disabilities in Africa continue to suffer human rights violations due to their disability status. And, although disability is a worldwide phenomenon, not much has been written on the subject in the African context.

   The main purpose of this paper will be to engage with the subject of disability rights under the African human rights system. In the main, the African human rights system is composed of three instruments: the African Charter on Human and Peoples’ Rights (ACHPR); the Protocol to the ACHPR on the Rights of Women (AWP); and the African Charter on the Rights and Welfare of the Child (ACRWC).

   Apart from scrutinizing the normative standards of the instruments in the African human rights system in light of the rights of persons with disabilities, this paper will also investigate some of the relevant jurisprudences emanating from the various supervisory organs within the African human rights system. For instance, the case of Purohit and Others v The Gambia from the African Commission on Human and Peoples’ Rights (African Commission) and some of the Concluding Observations from the African Committee of Experts on the Rights and Welfare of the Child (ACERWC) and the African Commission will be examined. Examples in the domestication of rights for persons with disabilities in selected African countries will be underscored, and the challenges and opportunities in implementing the rights of persons with disabilities will be interrogated. In
this respect, for instance, cultural beliefs and attitudes which interfere with the rights of persons with disabilities will be presented, too.

A common thread that runs through this paper will be the value of ratifying and implementing the Convention on the Rights of Persons with Disabilities (CRPWD) by African countries. It will be argued that a regional instrument specific to persons with disabilities in the presence of the CRPWD is redundant. In addition, until the realization of the ratification and implementation of the CRPWD by African countries, various ways of promoting and protecting the rights of persons with disabilities within the African human rights system will be proposed.

3. **Northern Ireland**: Colin Harper
   Disability Action

   “One Peace (Dis-)agreement and two single bills: Challenges in the legal implementation of the UN Convention on the Rights of Persons with Disabilities within Northern Ireland”

Implementing the UNCRPD through processes of law reform and legislative innovation in a small European legal jurisdiction, which is part of a much larger state, faces many challenges. This paper will look at 3 legislative processes potentially implementing the UNCRPD within Northern Ireland:

- The Northern Ireland Bill of Rights process, although much older, has become a key unfinished piece of business of the Good Friday peace agreement of 1988. There has been extensive engagement with this process on the part of the voluntary sector within Northern Ireland, but political engagement has been characterised by deep opposing views between unionists and nationalists. The relative lack of human rights experience and expertise within the disability sector has contributed to difficulties in evolving the Northern Ireland Bill of Rights in a UNCRPD compliant, positively implementing and promoting direction.

- The creation of a single equality bill in Great Britain has reinvigorated interest within Northern Ireland in a single equality bill for this jurisdiction. Several innovations within the GB Bill with respect to disability discrimination and equality possibly augur well for creative new approaches in any NI single equality bill. Driven in part by recent House of Lords and European Court of Justice judgments, the single equality bill is both consolidating and developing core equality law. A single equality bill for Northern Ireland has potential to significantly advance the legal implementation of UNCRPD, especially since the detailed drafting of its provisions will postdate UK ratification of the Convention.

- Northern Ireland is currently developing a new ‘Mental Capacity Bill’ which is intended to both replace the Mental Health Order (Northern Ireland) 1986 and to implement a similar statute regulating adult
decision-making capacity to those created in England & Wales (2005) and in Scotland (2000). The current proposal from the Department for Health is for a single bill which is 'capacity-based' in its approach to mental health issues, dealing with decision-making for all health issues using the same functional test of capacity. The paper will compare and contrast the emerging shape of this emerging legal capacity law with the standard set by articles 3, 5 and 12 of UNCRPD. The different approach taken by civil society and government in this process, compared to the Bill of Rights will be considered in the light of its apparent greater effectiveness in securing government agreement with calls from civil society for rights-based law. The different kind of process initiated by government will also be discussed.

The way in which these three legislative processes have interacted or failed to interact will be examined for lessons useful for developing implementation strategies for UNCRPD. In addition, the key role of processes initiated by government will be considered for their implications (Bamford Review of Mental Health and Learning Disability, Bill of Rights Forum ) along with the role of the national human rights institution (NIHRC). In conclusions, lessons will drawn for the kind of article 33 process necessary for effective implementation of the Convention.

4. **United Kingdom**: Tabitha Collingbourne
School of Law, University of Sheffield

"Contradiction in Terms? The UK, socio-economic rights and Article 19 CRPD"

The United Kingdom ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) in June 2009. One aspect of that Convention is that it fuses civil, cultural, economic, political and social rights to an extent not previously seen in the international human rights framework. The UK, however, is strongly resistant to incorporation of socio-economic rights into its domestic law. This paper examines the impact of this position on realisation in the UK of Article 19 CRPD (living independently and being included in the community).

Article 19 exemplifies the close integration of civil and political rights with economic, social, and cultural rights in the Convention and in people’s lives. Realisation, for all disabled people, of the kinds of freedom and choice that others take for granted requires not only housing options and personal support services, but also accessible transport, education, healthcare, financial provision and more: it requires the realisation of economic, social and cultural rights.

The UK has no written constitution. Although it has ratified all of the main international human rights treaties, the only treaty so far incorporated into its domestic law is the European Convention on Human Rights, which protects civil and political rights. There is thus no constitutional recognition of, or protection for, economic, social or cultural rights, which
are seen instead as principles and objectives to be realised through progressive social policy.

This perspective is reflected in current UK developments in the field of independent living. Strong policy moves to bring about radical changes in service provision - guided by disabled people and based on ‘personalisation’, choice and control - fit well with the Convention’s ethos. However, there is marked resistance to any acknowledgement that these policies have their roots in human rights law; and similar reluctance to introduce rights- based rather than welfare legislation. Tight eligibility criteria continue to leave many without support, and redress systems remain inaccessible and ineffective.

This paper argues that the UK government’s failure to incorporate economic, social and cultural rights into domestic law and policy, whilst at the same time ratifying a Convention which demands their full realisation, is simply not tenable. This tension threatens to impede realisation in the UK of Article 19, and indeed the rest of the CRPD.

**J: Regional & Comparative Disability Law (2)**

**Chair:** Professor Patricia Noonan Walsh (Adjunct Professor Centre for Disability Law and Policy, NUI Galway)

1. **Iceland:** Helga Baldvins Bjargardóttir  
Centre for Disability Studies, University of Iceland

“Implementing the CRPD in Iceland: Critical questions about legal capacity and the use of aversive intervention”

This paper focuses on the human rights of persons with intellectual and developmental disabilities. In particular it will address the rights of people who are seen as expressing “challenging behaviors” and are subject to aversive interventions, restraints and seclusion. It will reflect on some critical questions such as: Are these interventions necessary “treatment” or “therapy” or are they human rights abuses? To what extent are some of the routine institutional practices in treatment programs, group homes and other services violations of human dignity, autonomy, personal freedom and liberty? And to what extent are they necessary to protect the safety of the person and others? Persons with autism and/or intellectual disabilities are often subjected to aversive intervention, force and restraints. This is done in the name of treatment for the “challenging behaviors” and these individuals often suffer the deliberate use of pain, humiliation, exclusion and immobilization as a part of such “treatment.” The paper will discuss these critical questions in the context of the state’s obligations under articles 12-16 of the CRPD and placed in the context of Icelandic legislation and human service practices.

2. **Portugal:** Paula Campos Pinto
Law and policy around disability in Portugal are undergoing rapid change towards a model based on human rights for all. To fully achieve that transformation, however, it will take a long and arduous journey. This paper offers a critical discourse analysis (CDA) of the single most important policy instrument in the disability arena in Portugal: the First National Action Plan for the Integration of People with Disabilities and Impairments, 2006-09 (PAIPDI). Following Fairclough’s approach (1992; 1995; Chouliaraki and Fairclough 1999), a three-dimensional assessment is conducted encompassing the examination of the linguistic features of this text, the investigation of processes related to its production and consumption, and the discussion of the wider socio-cultural practice to which this policy document as a “communicative event” belongs.

Through an exploration of the discursive constructions of disability as a policy problem in this essential document, hidden values, assumptions, and ideologies, as well as the power relations that currently shape government actions towards people with disabilities in Portugal are revealed. This analysis demonstrates that while presented under a somehow different package - one in which a new discourse on rights is highlighted - there is much continuity in how the problem of disability is managed in the Portuguese society. Indeed, at a fundamental level it is still the state and the medical profession which hold the power to determine who is and is not disabled, and therefore who is, and is not, entitled to services, supports and benefits. Furthermore, the PAIPDI is entirely gender-blind, presenting people with disabilities as an asexual group, always talked about as a collective. Therefore, the specific interests and concerns of women with disabilities remain neglected. Despite these limitations, the adoption of the rights discourse on disability signals an important shift, reflecting the increased hegemony of the disability movement, not just nationally but also internationally. Thus by framing disability as a human rights issue for the first time in the Portuguese political discourse, the PAIPDI opens up for disabled people and their allies new and exciting possibilities for challenging and reshaping the power relations that in the past have sustained their domination. In this paper, as I highlight the gaps, tensions, and limitations that persist in the polity approach to disability in Portugal I suggest alternative ways of addressing these issues and, thus, I too engage in a dialogue that seeks to contribute for the continuing improvement of policy and law affecting people with disabilities in this country.
Serbia: Damjan Tatic  
Disability consultant at UNDP CO Serbia

“Law on Prevention of Discrimination against Persons with Disabilities in Serbia”

The paper discusses the recently adopted Law on Prevention of Discrimination against Persons with Disabilities in Serbia. Serbia’s Parliament adopted the Law in April 2006, marking a significant step in combating discrimination. This law was the 1st anti-discriminatory law Serbia adopted. The law prescribes for the general regime of prohibition of discrimination on basis of disability, particular cases of forbidden discrimination against persons with disabilities, judicial proceedings for protection of persons who had been victims of discrimination, sanctions (fines) for perpetrators of particular acts of discrimination in certain areas and measures that state and local authorities take in order to promote and encourage equality and social inclusion of persons with disabilities. Law defines terms “persons with disabilities”, “discrimination” (direct and indirect), „discriminatory acts”. Definition of persons with disabilities is based on social model of approach to disability. Part 2 of the Law regulates the general prohibition of discrimination. Articles 6 to 10 define forms of discrimination: Direct and indirect discrimination, violation of principle of equality of rights and duties, calling for and instigating discrimination, cases of severe discrimination as well as cases that shall not be considered discrimination.

The Law prohibits both direct and indirect discrimination. Law provides protection to victims of discrimination who are victimised solely because they requested or intend to request protection from past discrimination, or has offered to or intends to offer proof of discrimination. In article 8 Law prescribes that it shall not be considered discrimination to adopt provisions of legislation, decisions or specific measures aimed at improvement of status of persons with disabilities, their families and organizations, providing special support needed for realization of their rights under conditions of equality (clause 1). Furthermore, it shall not be considered discrimination to adopt or maintain measures and acts aimed at improving or eliminating the unfavorable situation in which persons with disabilities are. Part 3 of the Law prescribes for particular cases of discrimination that are prohibited. Discrimination is prohibited in the following areas: Proceedings in organs of public authorities (art. 11), participation and membership in civic associations (art. 12), access to public objects, places and services (arts 13 to 16), access to public transport (arts 27 to 29), health care (art. 17), education (arts 18 to 20), employment and labor relations (articles 21 to 26), family and marital relations (art. 30). The Law also prohibits discrimination of organizations of persons with disabilities (art. 31). Part 4 of the Law prescribes for the measures for promoting equality of persons with disabilities. The proposed measures were drafted and based on the UN Standard Rules for Equalization of Opportunities for Persons with Disabilities. Law prescribes for litigatious civic procedure in cases of discrimination on grounds of
disabilities in Part 5. Article 43 of the Law prescribes that lodger of complaint may request prohibition of carrying out of act that would constitute discrimination, cessation of continued or repeated carrying out of the act of discrimination (clause 1), removal of consequences of discrimination (clause 2), declaration that defendant carried out an act of discrimination (clause 3) and compensation of material and moral damages (clause 4).

4. **Russia:** Michael Rasell  
School of Health and Social Care, University of Lincoln  

“Scarred citizenship: disability law and policy in contemporary Russia”

Almost twenty years since the end of Soviet rule, disabled people are officially equal citizens in Russia. However, many disability and human rights organisations in the country complain that current laws and policies undermine the rights of people with disabilities. My paper looks at how ever-present tensions between guaranteeing rights and providing care are balanced in Russian social policy. It is based on my PhD thesis (to be submitted in March 2010) which explores how state welfare provision affects the social citizenship and everyday lives of disabled people in Russia.

I start with a historical discussion of disability policies in the USSR, namely how highly medical approaches and a productivist notion of citizenship led to the rejection of disabled people as ‘invalids’ and unproductive. They were excluded from society in harsh residential institutions designed to sustain the official myth that ‘there are no disabled people in the USSR!’ This in turn promoted hostile public attitudes towards disabled people.

A disability rights approach started to develop in Russian law in the late perestroika period and receiving formal rights was a key legal breakthrough in the early 1990s. However, the legal and policy changes took place in the context of severe socioeconomic dislocation and political uncertainty which prevented the overhaul of existing services. The resulting lack of detail and enforcement for new laws left the rights of disabled people unclear and unsupported, thereby creating spaces for discrimination in many fields.

Specific policy change came as a result of neoliberally tinged social reforms under Vladimir Putin in the early 2000s. Cash payments replaced Soviet-era entitlements to free social services and disability pensions were linked to official assessments of whether disabled individuals are ‘unable to work.’ Such moves imply an official conception of disabled people as passive and dependent with narrow medical and financial needs, thereby promoting an individualistic policy model that ignores wider social determinants of disability.
Ultimately, I suggest that the citizenship of disabled Russians is ‘scarred’ by the Soviet past in the form of legal expectations, professional practices and social attitudes. However, this is not a simple matter of Soviet legacies persisting into the new millennium. Rather, current policy represents a complicated reworking of older approaches with factors specific to the post-Soviet context. International influences have been weak to date and the UN Convention will have to take root upon this existing foundation of patchy progress and limited understanding of disability rights.

5. **Nigeria: Omolara Funmilola Akinpelu**  
Postdoctoral researcher, Burton Blatt Institute, University of Syracuse

“Human Rights and Persons with Disabilities in Nigeria: Beyond Policy Formulation”

This paper examines issues relating to human rights and persons with disabilities in Nigeria. It also discusses the need to go beyond formulating human rights policies and stresses the need to implementing such policies. Human rights refer to the basic rights to which all humans are entitled, often held to include the right to life and liberty, freedom of thought and expressions, and equality before the law. Human rights cover those individual entitlements and freedom that pertain to a person of his/her humanity, whether they are civil and political or economic, social and cultural. The Fundamental Human Rights as provided in the Nigerian Constitution (1999) are in harmony with the Universal Declaration of Human Rights adopted by the General Assembly of the United Nations in 1948 and 1966 respectively. It has been noted that societies’ low regard for the abilities of persons with disabilities has resulted in discrimination and stigma attached to disability, which pose great barriers in their participation in economic, cultural, political and social life.

In order to include persons with disabilities in the larger societies, there has been a dramatic shift over the past two decades in terms of their fundamental human rights. This shift to a human right’s perspective has been authoritatively endorsed at the level of the United Nations. This is reflected in several developments, for instance, the General Assembly declared the year 1981 as the “International Year of the Disabled” under the slogan “Full Participation and Equality”. In 1982, the General Assembly adopted the world Programme of Action concerning Disabled Persons which set the guidelines for a world strategy to promote “equality” and “full participation” by persons with disabilities in social life and development. As a follow-up to the World Programme of Action, the General Assembly, in 1983, adopted a resolution entitled “Standard Rules on the Equalization of Opportunities for People with Disabilities”. The Standard Rules explicitly take the International Bill on Human Rights (which comprises the Universal Declaration on Human Rights and the two international Covenants on Economic, Social and Cultural Rights and Civil and Political Rights) as their political and moral foundation (para.13). These formal statements constitute an important reference guide in
identifying the relevant obligations of state parties under the existing human rights instruments. These international policy documents aim at ensuring that “girls, boys, men and women with disabilities, as members of their societies, may exercise the same rights and obligations as others, and require states to remove obstacles to equal participation (para.15).

Also in 1993, the Vienna Declaration of Human Rights reaffirmed that “all human rights and fundamental freedoms are universal, and thus unreservedly include persons with disabilities”, and placed the active participation of persons with disabilities in all aspects of civil society explicitly in human right context. Nigeria is a signatory to most of these universal declarations of human rights policy documents. For instance, Nigeria became a signatory State to the United Nation Convention on the Rights of Persons with Disabilities on March 30, 2007. The fundamental question is has Nigeria implemented these human rights policies The purpose of this paper therefore is to examine the extent to which persons with disabilities in Nigeria enjoy their fundamental human rights. This paper will discuss cultural perspectives of disability with a view of presenting how persons with disabilities were treated in the past. The paper will also focus on how the Nigerian government and the Nigerian society accord persons with disabilities their human rights at present. The implications of current trends for future will also be discussed. This paper will contribute to the field of disability studies because it will give information about human right issues as they relate to persons with disabilities in a developing country such as Nigeria.

K: Bioethics & Disability

Chair: Dr. Richard Hull (Philosophy, College of Arts, Social Sciences, & Celtic Studies)

1. Aisling de Paor (Ireland)
   Ph.d Fellow, Centre for Disability Law & Policy, NUI, Galway
   “Genetic Discrimination in the Insurance and Employment Fields”

2. Carla van Os (Netherlands) (unable to attend)
   University of Leiden, Law Faculty
   “Prenatal testing on disabilities in the human rights perspective”

Prenatal testing is a shorthand expression for testing a fetus or embryo prior to birth. Prenatal testing is also employed to detect disabilities and fetal defects or to determine the gender of the future child. There is widespread evidence that prenatal tests revealing disabilities often result in the termination of a pregnancy upon the request of the future parents. How should these forms of selective abortion on grounds of disability be
judged from a human rights perspective? Does this have implications for the responsibility of States with respect to the availability and access to prenatal testing? Does the UN Convention on the Rights of Persons with Disabilities impose new duties on States in this respect? These questions will be answered in a PhD research, which places prenatal testing, focusing on Down syndrome, in a human rights perspective.

Situation in the Netherlands:
Currently in the Netherlands prenatal testing is offered to all pregnant women. The goal of prenatal testing is to ensure that all future parents are able to make informed choices about parenthood. About 50% consent to undergoing such testing. (Until 1 January 2008 only pregnant women older than 36 were offered the prenatal testing. Women older than 26 years or on medical indication the testing is paid by the insurance.) From this group there is approximately a 90% abortion rate after the fetus is diagnosed with Down syndrome. (M. Korenromp. Parental adaptation to termination of pregnancy for fetal anomalies (diss. Universiteit van Utrecht 2006), p 121)

Prenatal testing and eugenics:
Raz describes that prenatal diagnosis is a widespread phenomenon in Israel. In a survey 94% of the secular women older than 35 years performed amniocentesis. Raz interviewed representatives of organizations supporting disabled persons. He found that 82% of the respondents hold a two-fold view on disability: support of genetic testing in order to improve overall health and support of disabled persons after birth. Many respondents called the testing ‘eugenic’, meaning improving health. (A. E. Raz, ‘Disability rights, prenatal diagnosis and eugenics: a cross-cultural view’, Journal of Genetic Counseling, Vol. 14, No 3 June 2005.)

Human rights perspective:
The PhD study places the discussion about prenatal testing on Down syndrome in a human rights perspective. Human rights entail the obligation to maximally respect the autonomy of (pregnant) women. While being a bit vague on their precise legal status, unborn children are at the same time entitled to protection under human rights law. This PhD research will investigate the interaction between the effects of prenatal testing followed by selective abortion and the position of persons with Down syndrome, rather than on the rights of the fetus.

This study makes a comparison with the work of the UN Committee on the Rights of Child that has expressed the view that selective sex selection is a form of gender discrimination forbidden under Article 2 of the Convention of the Rights of the Child. The Committee recommended for example the Government of India to promote the social position of girls in order to prevent selective abortion on girls fetuses. (CRC/C/15/Add.115, 23 February 2000, Concluding Observations: India, para. 32 & 33.) The UN Convention on the Rights of Persons with Disabilities urges State Parties to take measures to raise awareness throughout society to foster the respect for the rights and dignity of persons with disabilities and to
combat stereotypes (Article 8). What do these obligations mean in the context of prenatal testing on Down syndrome?

3. Ciara Staunton (Ireland)
School of Law, NUI Galway

"A Superhuman Race? Pre-implantation genetic diagnosis and disability detection"

Pre-implantation genetic diagnosis (PGD) is the genetic testing of embryos created through in vitro fertilisation. Embryos with certain desirable traits are then selected for implantation carried out before the selection of embryos into a woman’s uterus. PGD is an alternative to prenatal testing (i.e. testing a foetus for genetic problems) and thus can avoid an abortion. Originally, PGD was requested to ensure that the embryos implanted would not have serious hereditary conditions linked to the X chromosome. However, most notably in the United States, this practice has now progressed with parents opting to choose an embryo with which they believe to have desirable traits and no "defects" such as a disability. While there is no direct legislative ban on PGD in Ireland, it is thought that it is prohibited and PGD cannot be carried out on embryos in this jurisdiction.

Much focus has been given to parents with a disability opting to implant an embryo, which has similar characteristics, such as deafness or dwarfism. This paper, however, will examine the potential impact PGD could have on the disability community with embryos, which carry a disability being discarded. Such a practice could lead to the belief that a life with a disability is a life not worth living. It will address the issue that a disability is not a medical problem but a social problem and will consider whether PGD should have a statutory ban in Ireland as it does not conform to society’s goal of inclusion and equality for people based on disabilities.

**L: Development Aid, Humanitarian Intervention & Disability**

**Chair:** Professor Nora Groce (TBC)

1. Jukka Kumpuvuori, Riku Virtanen (Finland)
Åbo Akademi University, The Institute for Human Rights (Kumpuvuori) and University of Turku, Faculty of Law (Virtanen)

"Human Rights, Disability and Development - Role of Various Actors in the Era of UNCRPD"

The article focuses on the complex picture of realization of human rights in the context of disability in development. Even before, and especially after, the initiation of the United Nations Convention on the Rights of
Persons with Disabilities (UN CRPD) the roles and responsibilities of different actors has remained unclear, both from the legal and political points of views.

The article departs from the practical scenario of different actors functioning in a complex setting of human rights, disability and development. The range of actors includes states, international organisations, donors, development cooperation partners, private sphere, individuals and organizations of and for persons with disabilities, to name some focal ones. The functioning of this network has significance in the realisation of human rights of persons with disabilities, since lot of that has to do with the mindsets of different actors, and efficient functioning being a good catalyst for exchanging views and affecting other’s mindsets.

The role of the donors is to, for example, to create and promote awareness about the obligations of accessibility and to ensure accessibility of persons with disabilities in their own actions. While the role of donors is in facilitating necessary knowledge and skills of local development partners in developing countries, the role of the organisations of persons with disabilities is to provide consultancy and to facilitate accessibility within development cooperation. In addition, the role of local partners and authorities is to monitor the implementation of accessibility obligations within all sectors of society and to promote possibilities of accessible building and inclusive education, to name a few. The role of institutes and research centres is to collect and to analyze information concerning disability in development. This creates a circle which benefits all the stakeholders.

The article identifies the legal positions of various actors, based on the doctrines of international human rights law, and concludes by setting a comprehensive research agenda on the topic. As the initiation of the UN CRPD has given a strong impetus to the field of disability in development, a vacuum exists in the theory and practice of identifying different roles of different actors in the field. The article contributes in filling a part of this vacuum, and thus has significance to disciplines of law and studies on disability in development.

2. Kristy Crabtree (United States)
   Episcopal Migration Ministries

   “The Economic Coping Mechanisms of Refugees in Protracted Displacement: Case Study of the Rohingya”

For refugees living in settlements or camps for decades, anxiety is a common attitude. Expressing their state of desperation as a result of this extended displacement, one refugee has likened the choice between living in refugee camps or maintaining a persecuted existence in their native country as a choice between ‘jumping into the river or the sea.” Ultimately, this has forced the Rohingya, an ethnic, Muslim minority from Burma, to live in a state of uncertainty – without hope for any real
solution to their displacement in Bangladesh and without the tools to provide for themselves in a safe, sustainable way.

For the Rohingya and the global population of refugees, one of the consequences of protracted refugee situations is the economic deprivation that results when the humanitarian relief structure decreases over the years. To cope with declining international aid, refugees often seek opportunities for income generation to meet their basic needs. In 2008, the author interviewed 127 individuals in southern Bangladesh. The study participants were comprised of primarily the Rohingya refugees, but also local Bangladeshis, and employees from non-governmental organizations. The objective of this qualitative study was to explore the desires and concerns of refugee populations surviving without adequate aid in order to explore risks associated with income-generating activities and the possibilities for livelihoods support. During the interview process, the author asked about the background of the interviewee as well as open-ended questions about current livelihood strategies, self-sufficiency pursuits, desires for the future, and the attitude of the local population toward the Rohingya. This case study showed that although there is no legal right to work for refugees in Bangladesh, nearly every refugee household was engaged in multiple forms of wage-earning employment as a coping mechanism to economic deprivations.

The case of the Rohingya refugees is illustrative of refugee coping mechanisms on multiple levels. Being faced with growing needs, inadequate international aid, and little opportunity for a durable solution, a majority of the Rohingya refugee households are finding ways to cope with prolonged displacement through the utilization of precarious livelihood strategies and these actions are likely representative of many other refugee populations around the world.

The author’s research examined the livelihood strategies of registered, unregistered, and self-settled refugees to discover current livelihood pursuits and potential opportunities to empower refugees through livelihood promotion programs. After identifying the current livelihood strategies of the Rohingya and their associated risks, the author will address potential obstacles to livelihood promotion programs, and make several recommendations to meet the economic challenges of refugee warehousing. In sum, the author supports the introduction of livelihood promotion programs that will not only stave off refugee “warehousing” but will also contribute to the local economy of the hosting country.

3. Graziella Van den Bergh (Norway)
   Bergen University College

   “Disability, health services and international collaboration: comparing comprehensive and community based rehabilitation approaches in Tanzania and the Sudan”

Historically, disability and rehabilitation have been conceptualised and organised in various ways, while involving professionals as well as laypeople. The model of Community Based Rehabilitation (CBR), with roots
back to the 1978 “Health for All” Declaration was designed to bring primary health care and rehabilitation to more people, especially those living in underserved rural areas. Health, education, livelihood, socio-legal issues, and empowerment and capacity building became key-domains in CBR. Tanzania and Sudan have different histories in relation to policies on disability and the involvement of professionals with people with disabilities (PWD) and communities. This is interesting in a comparative perspective.

The aim of the planned study is to analyse specific Tanzanian and Sudanese applications of CBR. The role of communities, of parents, of disabled people organisations (DPOs), of global discourses on human rights, government support, non-governmental institutions, multi-sectoral collaboration etc. are examined. The human resource implications of scaling up CBR are studied by focusing on the organisation of CBR services in the two countries. The role of public and private actors, as well as of national and international institutions will be examined.

First, documents and literature on CBR policies in the respective countries will be reviewed. The application of CBR principles is planned to be studied through focusing on local NGO’s being part of international networks, respectively Cheshire Home in Sudan, and CCBRT, a Tanzanian NGO pursuing a vision of “Comprehensive” CBR, combining specialised services with community services. Data will be collected through individual and group interviews, as well as questionnaires, and participatory research implying a “dialogic epistemology” is pursued. This implies collaboration with academic institutions; with professional associations and with organisations for people with disabilities (DPOs).

CBR is meant as a tool to offer equal access to rehabilitation services. To reach the vulnerable, sustainable frameworks and contextually appropriate competence need to be built. The paper will discuss preliminary findings on how this applies in the suggested models in Sudan and in Tanzania. The relation between the stakeholders of CBR programmes, such as for instance parents, PWDs, DPOs, and professionals (such as physiotherapists etc.), will be discussed comparatively, thus addressing professionalism and its contributions to the lives of PWDs at a local level. It will be assessed whether the desires of potential user-groups, correspond to professionals’ motivation and perceived roles, and to an appropriate use of skills. Given the brain drain, and considering how class formation and the distribution of power are related to health and social work, the issue is pertinent. The level of commitment to CBR in health ministries will be talked about, and services in both countries will be considered in light of a vision of equal rights and empowerment to all citizens. The models’ adaption to global and national health inequalities, as well as to national priorities, such as in time of an HIV epidemic, or post-war, is discussed. The study aims at making a bridge between organisational theory and anthropology, to show how different kinds of organisations provide different controls on their members.
People with disabilities are often excluded within humanitarian programs and services. When included, their needs are frequently considered as an afterthought. This exclusionary trend is true of humanitarian programs in general as well as programs targeted at refugee populations. This paper will focus on the findings of a study that combined refugee policy analysis with ethnographic research involving disabled refugees.

There are an estimated 10.5 million refugees around the world and people with disabilities comprise 10% of this population. Disabled refugees are more adversely affected by displacement and are often hidden within broader refugee populations. Yet, research involving disabled refugees is limited and little is known about their experiences when accessing humanitarian aid and other interventions targeted at refugee populations. This paper will present the findings of a research study that sought to understand the experiences of disabled Somali and Cambodian refugees resettled in the U.S., within the context of international humanitarian assistance for refugees and U.S. refugee resettlement policy and practices. Narrative data from 8 Cambodian and 7 Somali refugees were combined with archival data, documentary analysis, and information obtained from service providers and advocates. Findings revealed the challenges encountered by disabled refugees across different stages of the displacement process: in refugee camps, when applying for resettlement, and after resettlement in the United States.

The displacement journeys of the two refugee groups studied occurred at different moments in history. Consequently, the experiences of disabled people in both groups and their access to international humanitarian intervention, particularly third country resettlement were marked by important differences. Yet, once resettled in the U.S., disabled refugees in both groups experienced similar service and advocacy gaps. By contextualizing the voices of disabled refugees within the landscape of U.S. and international policy and practices related to humanitarian assistance for refugees, this paper will highlight: 1) how the broadening geo-political imagination of disability has influenced on-the-ground changes for refugees with disabilities; and 2) how ongoing dialogue and collective advocacy are essential to ensure diffusion and systematization of these changes within humanitarian policies and practices targeted at refugee populations both internationally and domestically within the U.S.
M: The Right to Accessibility

Chair: Rónán Kennedy (School of Law, NUI Galway)

1. Donal Rice (Ireland)
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   “Legislating for Web 2.0 – implications for the revamp of the Irish Disability Act (2005)”

With the 5 year review of the Disability Act (2005) to be undertaken in 2010, this timely paper will examine the treatment of web accessibility in Irish disability law. The Internet continues to grow in terms of its importance in the lives of most people. This is particularly true for people with disabilities, many of who can benefit from online to access to goods, services and information. The Disability Act (2005) requires that electronic information be provided in an accessible format on request to people with vision impairment to “whom adaptive technology is available”. Though this obligation on providing information on request is inline with other provisions in the Act, this paper will show how each element of this obligation is in some way problematic in terms of providing universal access to people with disabilities on the web.

Five years is a long time in the life of the Internet, given the 27 years since its inception. The past five years has seen the advent of online services such as social media sites, the proliferation of video content and of course ‘twittering’. The use of advanced web technologies is also changing the basic user interface of the web. The collection of technologies and user-interface advances which come under the general heading “Web 2.0” represent a paradigm shift in the way in which users interact with the web but also how the Internet delivers and presents information to the user. All these advances present particular challenges to people with disabilities, challenges that were not prevalent during the drafting of the Disability Act (2005). And it is not just the technological landscape that has changed. International law, European Commission policy and international web standards have all progressed significantly in this time.

The UN Convention of the Rights of Persons with Disabilities places ICT accessibility on a par with other forms of accessibility such as the built environment and transportation. The Convention contains specific dispositions and guidance to State Parties on web accessibility including the right to access public information in electronic format. Article 9 contains a definition of accessibility that includes reference to “information and communication technologies”. Article 21 contains requirements for State Parties to promote the accessibility of content more generally provided on the Internet.

The second version of Web Content Accessibility Guidelines by the W3C was made an official W3C recommendation in December 2008. Billed as
being ‘technology agnostic’ and more precisely testable, the new guidelines are a major step forward in terms of what technologies can now be considered to be accessible on the web and ways in which content such as video should be produced. The European Commission has recommended that all member States adopt these as their national guidelines in order to avoid market fragmentation across Europe.

This paper will discuss the implication of the technological, legislative and policy changes for the revamp of the Disability Act (2005). It will ask what is achievable in this current revamp and point to other measures that need to introduced in Irish disability equality legislation in order to provide sensible, sustainable, measurable and future-proofed regulation on web accessibility.

2. Martha Banda-Chalwe (Australia)
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   "Structures for promoting accessibility to enable participation by persons with disability in developing countries"

For decades persons with disabilities (PWD) have been the largest, poorest minority group globally and are distinguished in almost every category of their disadvantaged status. The inaccessible environment has contributed to the exclusion and disadvantage in education, training, employment, leisure, civic, religious, political and economic life thereby denying their participation in society/community and full enjoyment of their rights. Consequently, the provision of access to public buildings for persons with disabilities is becoming more important in developing countries as governments recognise their limited attention to the needs of PWD.

The basis of this paper is the UN Convention on the Rights of Persons with Disabilities (CRPD) and the UN Declaration on the Rights of Disabled Persons. Through these instruments, and in particular Article 9 of the Convention, the UN expresses in strong terms the prohibition of discrimination of PWD in all spheres of life. Article 9 recognises that accessibility enables PWD to live independently and participate fully in all aspects of life. The UN calls upon member states to adopt the CRPD as the basis and frame of reference for the protection of rights of PWD and ensuring full participation in society/community.

The role of the environment in facilitating or hindering participation by PWD within society/community, this paper argues, is reflected in the accessibility of public buildings, services and facilities. Additionally, there could be no meaningful participation by PWD without accessibility and positive life experiences. Literature indicates that inaccessibility of public buildings impacts negatively on the participation experiences of PWD and contributes to the exclusion of PWD from all spheres life. The sources of exclusion are partly linked to the policies, practices in the development, design and construction processes. The question is, how much exclusion...
or lack of participation by PWD is attributed to inaccessibility of public buildings? Disability antidiscrimination legislation, policies, regulatory mechanisms and monitoring systems have been identified to be some of the critical elements in the process of promoting and improving accessibility for participation by PWD within society/community by the World Bank, UN CRPD, WHO, the Australian Disability Discrimination Act of 1992, the Americans with Disabilities Act of 1990 as amended in 2008 and the United Kingdom Disability Discrimination Act of 1995.

The purpose of this paper is to provide an analysis of the systems used to achieve accessible public buildings and identify strategies used to promote accessibility for participation in both developed and developing countries using Australia, United States of America (USA), United Kingdom (UK), South Africa (SA), Zimbabwe and Zambia. Experiences, opportunities and challenges in the process of implementation and monitoring mechanisms will also be examined in order to identify strategies best suited for developing accessibility standards, processes and practices in Zambia and other developing countries.