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# European Society for Disability Research

Third Annual Conference

## Exploring Disability: Epistemologies, Policies and Politics

Lisbon – Portugal, 3-4 July 2014

Instituto Superior de Ciências Sociais e Políticas  
Pólo Universitário da Ajuda  
Rua Almerindo Lessa  
1300-366 Lisboa

## ABSTRACTS



Instituto Superior  
de Ciências Sociais e Políticas  
UNIVERSIDADE DE LISBOA



**CAPP**  
Centro de Administração  
e Políticas Públicas



Observatório da Deficiência  
e Direitos Humanos  
Disability and Human Rights Observatory

**FCT**  
Fundação para a Ciência e a Tecnologia  
MINISTÉRIO DA CIÊNCIA, TECNOLOGIA E INOVAÇÃO

# 3 July

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## Plenary Session 1

### **Disability Rights, Development and Democracy**

#### ***The Disability and Development Gap***

**Author(s):** Nora Groce and Maria Kett, The Leonard Cheshire Disability and Inclusive Development Center, University College London

#### **Abstract:**

While international development efforts up to and including the Millennium Development Goals have improved the lives of millions since 2000, there has been little attention paid to the systematic inclusion of the world's 1 billion people with disabilities in these efforts. In this presentation, based on both literature review and a series of field projects in Africa and Asia undertaken by the Leonard Cheshire Disability and Inclusive Development Centre over the past three years, we argue that in many countries, lack of inclusion of people with disabilities in ongoing development efforts has resulted in an ever-widening 'disability and development gap.' While millions of non-disabled people worldwide increasingly benefit from improvements in health, education, economic development, communications and human rights, people with disabilities who have not been included in these development efforts are lagging increasingly behind their non-disabled peers. We further argue that unless specific measures are taken to ensure the inclusion of people with disabilities in current international development efforts and in the upcoming Post-2015 agenda, and unless these are carefully monitored to ensure their proportional representation; people with disabilities are at risk of becoming poorer in both relative and absolute terms as their non-disabled peers begin to rise out of poverty. In light of this growing gap, we will argue strongly that researchers in disability have a unique role to play, working in collaboration with a range of stakeholders, including disabled peoples organisations, in defining and documenting this gap and in working with governments, UN agencies, and civil society to foster meaningful and equitable inclusion.

#### ***Political Participation and Disability Rights in the European Union***

**Author(s):** Mark Priestley and Ema Loja, Leeds University

#### **Abstract:**

The 2013 European Year of Citizens and the 2014 European elections highlight citizenship and participation rights in public and political life. Such rights are conveyed in the European

Charter of Fundamental Rights, while Article 29 of the UN CRPD obliges States to ensure political rights, including through engagement in non-governmental organizations; political parties; free and accessible voting procedures, facilities and materials; standing for election and holding public office. The European Disability Strategy 2010-2020 is also committed to address the accessibility to voting. Drawing on the UN monitoring typology of 'structure, process and outcome' indicators, the paper examines the situation within the EU. The evidence draws on European survey data and on primary research in the EU Member States. Formal progress has been made, with almost all EU Member States ratifying the CRPD but there remain significant barriers to full and free participation for all disabled people. There is a need for key stakeholders to be better informed on disability equality and greater accessibility is also essential, for example in polling stations, voting procedures, party manifestos or political broadcasts. Disabled people constitute up to one quarter of the European electorate and, on average, are more likely to vote than the general population and to engage with current affairs (but this is closely related to their older age profile). Those with more severe impairments are much less likely to exercise their rights and barriers to their participation must be challenged. Many disabled people are socially engaged through volunteering, protests, petitions and political meetings but they are less likely to have trust in Parliament or to be satisfied with the way democracy works. Creating meaningful engagement for disabled people and their organisations in political process is a CRPD obligation, and such engagement could help address some of the challenges posed in this paper.

### ***Which Theory of Democracy for an Inclusive Society? A Pragmatist Approach***

**Author(s):** Jean-Philippe Cobbaut and David Doat, Center for Medical Ethics- Lille Catholic University

#### **Abstract:**

It should not be stressed anymore today that political theories of the modern contractualist tradition, from Thomas Hobbes to John Rawls, have provided substantial justifications to our Modern democratic system. Nevertheless, despite such indisputable gain, scholars from both the disability studies and the care studies have continuously pointed out, for several decades, the inability of the contractualist tradition to set up the principles of a genuinely inclusive society. From this perspective, the aim of this communication will be twofold, both theoretical and practical as it is required by the pragmatist approach that will be developed. On the theoretical level, we will emphasize the argumentative kernel of the main criticisms that have been levelled by scholars (Shakespeare, Kittay, Nussbaum) against the contemporary

contractualist thought that informs most of nowadays social policies in Occident. We will stress in particular what may be seen as the anthropological overlooked prejudice on the basis of which the participation of disabled people in the decision making-processes of modern societies is not envisaged in the Theory of Justice of John Rawls. From a practical perspective, we will then present the democratic experience of the settlements of “Hull House”. These community service centers were founded in Chicago in the last century by Jane Addams – a colleague and friend of John Dewey – and constitute one of the most remarkable implementation of a new kind of both participatory and inclusive form of social democracy. This experience will be analyzed through a care (Tronto), capability (Sen, Nussbaum) and non-domination (Petitt) triple focus, in order to highlight how a genuine concern over social and political challenges raised by the construction of a more inclusive society, implies not only a necessary transformation of the anthropological grounds of current policies, but also a shift in the practical ways we “make democracy” in daily life.

### ***Developing a Framework of Human Rights Indicators in the field of Disability***

**Author(s):** Maria Engrácia Cardim, Paula Campos Pinto, Diana Teixeira, ISCSP/ULisboa

#### **Abstract:**

Article 33 of the UN Convention on the Rights of Persons with Disabilities specifically calls upon member states to establish a framework to monitor the implementation of the Convention. This requires a set of qualitative and quantitative indicators to measure progress in the implementation of the norms and principles of human rights as stated in the convention. Disability Indicators are defined as “a piece of information used in measuring the extent to which a legal right is being fulfilled or enjoyed in a given situation” (Green, 2001:1065). Indicators are methodological tools empirically supported that aim to provide information about persons with disabilities everyday life and the compliance with human rights under the law. They serve as a tool for policy design and policy evaluation and provide a better accountability for public interventions regarding disability issues. Both quantitative (numerical or statistics-based) and qualitative indicators are necessary to reveal how human rights are being upheld (Green, 2001).

To address this challenge, our team led a holistic monitoring of the current status of disability rights along three strands: critical analysis of law and policy; social representations; daily life experiences of persons with disabilities, in Portugal. This triangulation allows us a better accountability about the fulfillment of the law. Indeed, brought together these three areas offer a holistic picture that enables us to examine how human rights are being complied, what

are the key factors in the process and how citizens experience them. This enables a better assessment of the progress already made a better evaluation of what needs yet to be done.

On the basis of this knowledge, and a literature review on human rights and disability rights indicators, we designed a framework of qualitative and quantitative indicators to monitor the CRPD. A preliminary version of this framework will be presented and discussed in this paper.

#### **References**

Green, M. (2001). What We Talk About When We Talk About Indicators: Current Approaches to Human Rights Measurement. *Human Rights Quarterly*, Volume 23(4), 1062-1097.

# Parallel Sessions

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## PARALLEL SESSION A.1

### Disability, policy and politics

#### ***(Self-)Subscription to the CRPD as Meta-Code?: A Linguistic Dispositif's Effects on Agency through Human Rights Discourse(s)***

**Author(s):** Daniel Pateisky, Martin-Luther-University, Halle-Wittenberg, Graduate School, Society & Culture in Motion

#### **Abstract:**

With the adoption of the UN Convention on the Rights of Persons with Disabilities(2006) came a big step in the extension of international human rights legislation as well as in disability rights promotion. Human rights discourse and legislature has expanded since the mid-20th century to become an almost universally agreed and at times strategically implemented norm reaching at times a level of unquestionable “absolutism” (Joas 2004:397), The drafting of the CRPD did ,revolutionarily’ include the persons and groups directly concerned.. With prevailing notions of group othering that PwDs – and therefore DPOs – find themselves subject to and at times ‘necessarily’ drawing upon to further given aims – thereby reiterating such processes – came also the mainstreaming of linguistic coding that tends to designate social and political roles.

While the individual PwD – and a majority of other humans, for that matter – might not always have a proficient knowledge of the human rights circumstances and texts underlying international HR standards, an institutionalisation of shared coding is underway. By means of given types of political phrasing, its translation, accessibility measures and activist re-formulation these guiding notions can cause (if all goals are met) for increased agency as well as inevitable subscription to legal/political categories.

It is with respect to the concept of meta-code(s) (Rottenburg 2005, 2009) and World Society Theory (cf. Luhmann 1971; Meyer and Jepperson 2000) that this presentation wants to investigate (1) whether a variety of positions in disability rights discourse and activism can be brought together under unifying linguistic practices as provided by the CRPD; (2) how linguistic identification through a group and solidarity based on alleged homogeneity can influence the manner in which PwDs’ self-imagery is shaped, and how it synchronously frames discursive universality; and (3) how the conferment of such ideas, i.e. their ‘translation’ between

individual and institutional levels, can impact on the framework that international HR legislation wants to provide.

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***The intertwining of disability and neo-liberalism: The case of the Japanese inclusion policy***

**Author(s):** Anne-Lise Mithout, Paris-Dauphine University / Hiroshima University

**Abstract:**

In the 2000's, Japan reformed its whole social welfare system according to neoliberal principles. At the same time, it engaged in a new disability policy based on the orientations of the Salamanca Statement.

Implemented through the 2006 "Law on support to autonomy for people with disabilities", the combination of both these factors has resulted in a system based on the concept of tōjishashugi, literally "the person herself –ism". It is focused on the disabled person as an individual with special needs and aimed at promoting autonomy and social participation, following in this way the social model of disability and the perspective of empowerment. Nevertheless, the "autonomous individual" is in practice specifically conceived as an "autonomous consumer" of services she has the opportunity to choose and to the cost of which she has to contribute, following the purpose of balancing rights and responsibilities, in a way somehow similar to the situation in the UK as analyzed by Owen and Harris (2011).

How do neo-liberalism-based inclusion practices at the same time match and contradict the disability rights perspective?

This paper will analyze the reform itself, the critics and debates it raised among Japanese disability rights activists before it was voted, and its consequences in practice, eight years later.

Through the example of Japan, it aims at contributing to a wider debate about the intertwining of disability and economic issues that arises in European countries too and was mainly tackled in the UK.

### ***Handicap and Segregation: A Franco-American Dialogue***

**Author(s):** Roberto Domingo Toledo, Grhapes - Cermes3

#### **Abstract:**

The international history of “handicap” stigmatization and racial-based stigmatization are heavily intertwined. Furthermore, their histories involve complex mixtures of political and scientific controversies. In this presentation, I will focus on “conduct disorder,” a particularly hazy handicap category that was explicitly associated with inferior races and subhuman behavior in its earliest formulations. I will begin with a brief history of political intersections between racial and handicap-related politics, such as the modeling of U.S. “inclusion” disability upon the desegregation laws that African-American communities fought for during the Civil Rights movement.

Next, I will discuss how recent political controversies are putting questions of handicap, race, and segregation on the agendas of national Public Health initiatives again in the U.S. and France. I will focus particularly on the way in which two Public Health research documents published in France in 2005, “Child and Adolescent Conduct Disorder” (INSERM, 2005) and “Treating Psychopathy” (Haute Autorité de Santé, 2005) situate themselves both in respect to the history of handicap theories rooted in scientific racism (Lambroso, Morel) and with current sociopolitical issues in de facto segregated neighborhoods. I focus especially on the neighborhoods that received international attention due to the 2005 “riots.” Conduct Disorder is the Anglo-American term that replaced “psychopathy” in their literature, and it is commonly referred to by the more vague concept of “behavior disorder,” a term that is used liberally by professionals working in poor segregated neighborhoods in France. The 2005 Law on Handicap officially classifies “behavior disorder” as a cognitive handicap (Loi n° 2005-102 du 11 février 2005).

## ***Paradigm Shifts in Germany Disability Policy***

**Author(s):** Laura Landon-Favatas

### **Abstract:**

This paper will investigate the shift between two basic policy orientations toward disability in Germany: a traditional social welfare model (i.e., medical or rehabilitation model), originating in Western Europe, and a civil rights model, originating in the United States and Great Britain (Heyer, 2002). This paper will then consider to what extent the recent shift towards a civil rights (social justice) model has fulfilled its promise to individuals with disabilities in German, and what extant practices and legislation may be revised to improve the quality of life for these individuals. It is important to consider, while social and legal paradigms may be gradually shifting to support the civil rights of individuals with disabilities, according to many scholars, within the current policy paradigm, 'Germany falls squarely into the welfare model in its approach to legislating disability rights' and 'follows a difference or special-treatment doctrine' (Heyer, 2002, p. 728). This paper will unpack how this affects individuals with disabilities in Germany with regards to their current employment and education status and physical access, or barrier-free attainment of social justice. Ecological factors influencing this shift in policy will also be considered.

<sup>1</sup> All de informants have personal assistance, a person who help them to do the everyday tasks.

## **PARALLEL SESSION B (SESSION IN ENGLISH)**

### **Advocacy, disability activism, and the voice of persons with disabilities**

#### ***Inclusion, exclusion and rural idylls***

**Author(s):** Liz Ellis, Faculty of Health and Social Care, The Open University, Milton Keynes, UK

### **Abstract:**

This paper explores some of the emergent findings from an inclusive research (Walmsley & Johnson, 2003) project involving a small group of co-researchers, all of whom identify as having learning difficulties, living in a rural area in the south west of Britain. The field site is characterized by extremes of economic deprivation and immense personal wealth, in part due to its post-industrial but picturesque, costal location. I will outline how we used mobile interviewing methods to embed the research firmly within the 'place and space' of the co-researchers' local neighbourhoods and to help promote a more equal research relationship. There will be a discussion of how notions of the rural idyll worked to influence the choices made by the co-researchers and their parents relating to where they lived and were educated

and how those choices supported the autonomy of the co-researchers. I will illustrate how the co-researchers at times both challenged the rural idyll whilst simultaneously supporting the hegemony around the mythologising of the idyllic and cohesive rural community.

The co-researchers' histories of institutional inclusion/exclusion and the ways in which they continue to negotiate living inclusively within their communities will be explored. This will be juxtaposed with the rapid changes being experienced by the co-researchers and other disabled people living in the UK as a result of wide-ranging welfare cuts.

### ***No voice, no rights, in America: "Eugenics" and the epistemology of disability in the early 1920s***

**Author(s):** Luiz Castro-Santos, Instituto de Medicina Social, Universidade do Estado do Rio de Janeiro (State University of Rio de Janeiro)

Lina Faria, Departamento de Medicina e Fisioterapia, Universidade Federal de Juiz de Fora/GV (Federal University of Juiz de Fora at Governador Valladares).

#### **Abstract:**

This proposal seeks to unveil a long period of denial of basic rights to those that were considered socially inadequate, in early twentieth century "America" – a denial of voice, as well as of civil, political, and social rights to women and men who were considered "defective, dependent, and delinquent." We focus on the life and militant action of a/an (in)famous "eugenicist", a one-time scientist and consultant at the Carnegie Institution, H. H. Laughlin (1880-1943). Laughlin was influential among the academic circles of his time; in 1921, he published an article in the respected journal *American Journal of Sociology*, titled "The socially inadequate: How shall we designate and sort them?" He was an expert eugenics agent to the US Committee on Immigration and Naturalization in the early 1920s, worried about the "excessive" insanity among Eastern and Southern European immigrants. He was even more influential upon the political climate of his time. Laughlin succeeded in propagating ideologies and laws of compulsory sterilization in several states, aiming at the "unfit" members of the population, including the "feeble-minded," the "alcoholics," and the blind, deaf, and "deformed" persons. Our presentation will briefly examine the impact of his compulsive, obsessive, and moral cleansing ideas and proposals in the US and Europe. A question should be posed: do these ideas and proposals still emerge today, disguised or manifest in the "selective" policies against immigrants from Southern and Eastern Europe, and the Middle East? Should we consider that these deep waves of distrust toward the "different" may fuel anti-disability rights campaigns today? Our presentation will bring available evidence, from widely read

newspapers and the web, to suggest that these epistemologies of suspicion (Allison Scott-Baumann) and ideas of “racial integrity” still loom among us today.

***Intercession, emancipation and participation: Deaf modes of vocality and active citizenship in the nineteenth century & now***

**Author(s):** Goedele Declerck (UGent), Josephine Hoegaerts (KU Leuven)

**Abstract:**

“Parliament”, Mladen Dolar has noted, “is derived from the latin *parlare*. It is a place reserved for speech”. In this paper, we aim to examine the effects of the pervasive metaphors of voice and speech in political practice on the representation of political competence, emancipation and participation of those considered ‘voiceless’ (particularly the deaf). We also aim to explore ways to think beyond these speech-centric metaphors in order to create new roads toward political participation and critical citizenship for ‘conventional’ speakers as well as those usually heard as lacking speech. In doing so, we propose to create a political space for meaningful silence, in which the onus in political practice is not on the speaker, but on his audience. Rather than looking for ways to make the voiceless audible, this paper ultimately proposes to ‘hear’ and ‘see’ differently. We will set out to develop these ideas on vocality and political participation in three parts, envisioned as a conversation between the perspectives of political history and Deaf studies. In a first, historical, section, the establishment of the metaphoric interconnection between speech and citizenship is laid out, and contrasted with notions of voicelessness and the deafs’ perceived need for intercession. The second section shows how, more recently, the Deaf community has claimed a voice for itself and is involved in the creation of social and political agency, and political representation. In the third and last section, we explore the problematic notions of elocutionary and rhetorical assimilation inherent in ‘vocal’ representations of politics, and we consider the possibilities of active, meaningful silence as a road toward political participation beyond speech. We will do so, concretely, by confronting ‘traditional’ notions of parliamentarism with the current project of a ‘Deaf Parliament’ in Flanders, where intergenerational meetings between older and younger members of the Deaf community are resulting in exciting places of ‘silent’ communication and memory, and opening up new perspectives on the collusion of political practice and human rights.

## PARALLEL SESSION C (SESSÃO EM PORTUGUÊS / SESSION IN PORTUGUESE)

### Sexualidade e Vida Familiar/ Sexuality and Family Life

#### ***Attitudinal factors and participation in sexuality of adults with Cerebral Palsy***

**Author(s):** Daniela Lopes, Associação do Porto de Paralisia Cerebral (APPC) and José Alvarelhão, Escola Superior de Saúde da Universidade de Aveiro (ESSUA)

#### **Abstract:**

Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to nonprogressive disturbances that occurred in the fetal or infant developing. Cerebral palsy does not affect the desire or the level of sexual functioning. This health condition can change or limit the ability of people in the performance of sexual activity and intercourse. The aims of the study are: describe the participation of adults with cerebral palsy in romantic and sexual activities; describe the impact of attitudinal factors in participation. Forty-two adults with Cerebral Palsy (14 females and 28 males) with a mean ( $\pm$  SD) age of  $32.4 \pm 7.9$  years were recruited by invitation at Cerebral Palsy Association of Porto (APPC). 73.8% of participants who reported having had a romantic relationship in their life, 21.4% remain in the moment of data collection. Most participants (69.0%) have had sexual experiences in their lives, with 26.2% of the participants, all male, have attended to prostitution services. Both in terms of romantic relationships and gender, participants who have had these experiences were mostly male (64.5% and 75.9%), able to walk without human support or product support (61.3% and 69.0%), have intelligible speech (58.1% and 62.1%) and do not reside in institutions (71.0% and 75.9%). People identified as "those who have or have had" attitudes that somehow constituted a barrier to participation in the sexuality of adults with cerebral palsy were: parents, siblings, grandparents, colleagues or acquaintances and auxiliaries. In knowledge about sexuality, the results obtained by all participants were  $\bar{X}=13,2 \pm 2,10$ . The results indicate that participation in sexuality is higher in the group of individuals that have fewer limitations in activities of mobility and communication. Knowledge about sexuality seems to facilitate participation in romantic and sexual relationships.

### ***A sexual education program with a group of people with intellectual disabilities in residential care***

**Author(s):** Raquel Alveirinho Correia and Maria Conceição Oliveira, Associação Portuguesa de Pais e Amigos do Cidadão Deficiente Mental - Castelo Branco

#### **Abstract:**

Children, young people and adults with intellectual disabilities have the right to receive information and support about sexuality, relationships and reproductive health. This work describes a sexual education program developed with people with intellectual disabilities who live in residential care. The program was composed by 10 weekly sessions and the themes were defined after an individual interview done with all the participants. The methodology used was based on group dynamics, group discussions, role-plays, quizzes and exploration of materials. The themes involved biological aspects like the body, modification along the lifecycle and reproductive health, and relational aspects like feelings, different kind of relationships and different kind of ways to show affection. The participants were 14 persons with intellectual disabilities, divided in two groups and with ages between 17 and 41, 9 women and 5 men. By the analysis of the session's reports, it's possible to observe that the participants were very motivated and participative, especially in the sessions about the relational themes. Participants expressed interest in continuing the program because they could clarify their doubts and demystify some wrong ideas. People with intellectual disabilities should have the opportunity to benefit from sexual education programs, because they are sexualized individuals too. It's important to apply different and active methods, and use accessible language. As this population may present greater difficulties in social skills, it is essential to work further the relational aspects.

### ***Supporting resources for mothers of youth or adults with disabilities***

**Author(s):** Zélia Marcos e Paula Mena Matos, Faculdade de Psicologia e Ciências da Educação da Universidade do Porto.

#### **Abstract:**

The urgent concern towards the experience of mothers with disabled children, as central figure in the family relationship and in child and adult care, lead to the conception of a study about the disability support resources.

The living of these mothers may be affected in order to devote to the permanent care of the needs of a child with disabilities, disregarding other roles in their life. Concerns about their children's support resources and future, are important subjects for these mothers, in the extent as they wonder who will take care of their children when they no longer manage to

continue to ensure these same care for which they were responsible throughout their life. For this study, 12 mothers of youth or adults with severe or profound cerebral palsy, aged between 19 and 39, enrolled in the Centro de Reabilitação de Paralisia Cerebral do Porto, in Associação do Porto de Paralisia Cerebral, were interviewed. The mothers seem to consider that there are gaps in the support resources for the disabled and that the approach or awareness to deal with disabilities in society should also improve. The breaking of architectural barriers, the procurement of assistance products (wheelchairs, shower chairs, ...), the increase of the family benefits and social disability pensions, and also by building more institutions of occupational activities and caregiver relief programs are some of the intervention areas.

The funds for the disability area have been suffering severe cuts and the economic power of the households has also decreased, so, leisure contexts and occupational integration in institutions, although fundamental to relieve the caregiver, becomes a economic hardship for these families.

### ***Quality of life for families with children/youth with autism spectrum disorder***

**Author(s):** José Miguel Nogueira, PhD student in Public Policy with a thesis in the area of quality of life of people with disabilities at ISCTE - Lisbon University Institute/ Cabinet of Strategy and Planning, Ministry of Solidarity and Social Security

#### **Abstract:**

This research aims to analyze the impact of autism spectrum disorders (ASD) in families with children and youth (0-25 years) with ASD, in the District of Setúbal (Portugal). The impact will be evaluated on a multidimensional perspective, following the work on the concept of quality life from WHOQOL Group (UN). The study includes quantitative and qualitative methodology. It correlates statistical sources and other information with the data obtained through a survey of a sample of about 100 families with children/youth with ASD (October and November 2011). The results indicate a strong impact of autism on the quality of life for families in all study dimensions. The research shows a negative impact on quality of life for families in material and financial conditions, physical and emotional well-being, career progression, feelings of injustice, social participation and self-perception of happiness. The quality of life remained in the relationship with the family and the spouse, interpersonal relationships and beliefs about himself. The ASD improved quality of life aspects such as interest, knowledge and exercise of rights on disability, autonomy to make decisions and be able to deal with stress. Other dimensions are contemplated: a detailed characterization of the child/young with ASD and all family members (household composition, relationship status, academic qualifications, occupation, income and leisure) the impact of diagnosis in the family wellbeing, medical and

therapeutic processes, school inclusion, public support, social participation, and the adequacy and implementation of legislation. The study evaluates also the strengths and weaknesses of the Portuguese public rehabilitation system and demonstrates how a good law in theory may not solve the problems of families in practice due to the allocation of insufficient public resources, both financial and human resources.

## **PARALLEL SESSION A.2 (AUDITORIUM, GROUND FLOOR)**

### ***Disability, policy and politics / Deficiência e políticas públicas***

#### ***From reparation to revocability. New rehabilitation policies in the Swiss invalidity insurance***

**Author(s):** Isabelle Probst, University of Applied Sciences and Arts Western Switzerland (HES-SO), University of Health Sciences (HESAV) and Jean-Pierre Tabin, University of Applied Sciences and Arts Western Switzerland (HES-SO), EESP Lausanne

#### **Abstract:**

According to the new doxa linked with the “activation turn” (Bonoli, 2013) in social policies, the Swiss disability insurance (DI) was revised in the 2000s and in the 2010s in order to reduce the number of pensions accorded and to increase the employability of persons suffering from a health problem or a handicap. These revisions set new eligibility criteria for benefits and introduced new occupational rehabilitation measures. With a perspective inspired by the disability studies approach (Weisser et Renggli 2004; Waldschmidt et Schneider 2007 ; Bösl et al. 2010), we aim at discussing the consequences of these revisions on the conception of invalidity and rehabilitation. Our analysis relies on three types of data: legislative sources (laws, bills proposed by the Federal Council to the Parliament), statistical reports and evaluative studies produced on behalf of the administration.

We will begin by describing the prevailing conception of rehabilitation at the introduction of DI in 1959 (Lavanchy, in press) and we will show that it was based on the idea of reparation. We will then analyse the political discourses of the 1990s in order to show the construction of psychic disability as a problematic category based on the interpretation of administrative statistics. This construction legitimized new conceptions of occupational rehabilitation and lead in the 2010s to a redefinition of disability as a revocable statute. Discussing the nature and the scope of the recent changes, we will conclude that a new social policies’ paradigm is

emerging, which fundamentally changes the experience of the persons asking for or receiving DI benefits.

***Protection of the social rights of persons with disabilities from an international, European, and domestic law perspective***

**Author(s):** Nuria E. Ramos Martín, Assistant Professor, Department of Labour Law and Amsterdam Institute for Advanced Labour Studies, University of Amsterdam, the Netherlands.

**Abstract:**

This paper deals with how the protection against discrimination on grounds of disability in employment and social matters is covered by several legal instruments at different levels, in particular, the ILO Convention No. 159, the UN Convention on the Rights of Persons with disabilities, the Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation and, in the Netherlands, by the 2003 Act on equal treatment on the grounds of handicap or chronic illness. This paper includes an analysis of the legal implications for the EU and national levels of the approval on behalf of the EU of the UN Convention on the Rights of Persons with disabilities by Council Decision 2010/48/EC. This study addresses the implications of the multi-level regulation of the protection of persons with disabilities since the UN Convention covers protection against discrimination on grounds of disability not only in employment and occupation but also in social security and social protection. Moreover, the multi-level regulatory debate is especially relevant since there is a new proposal for an EU Directive extending the protection against discrimination based on disability also to social security and social protection and recent case law of the CJEU (Ring C-335/11) establishing that the provisions of the UN Convention have primacy over secondary EU law.

The main research questions for this paper are:

- (1) What shift is taking place in the levels at which social protection of persons with disabilities is being regulated?
- (2) What consequences does this shift have for the possibilities of domestic regulation and of self-regulation by the social partners and other organisations at the national and European level?
- (3) What is the real impact on the improvement of the social rights of persons with disabilities of the international legal framework in this field?

***Legal Innovation to promote the employment of physically disabled people: an inside perspective***

**Author(s):** Patrícia Neca, ISCTE – Instituto Universitário de Lisboa; Paula Castro, ISCTE – Instituto Universitário de Lisboa, and Paula Campos Pinto, Instituto Superior de Ciências Sociais e Políticas/ULisboa

**Abstract:**

People with physical disabilities have more difficulties in getting a job than people without any disability. Because of this, many countries are implementing affirmative action laws that aim to promote the employment of this group, as is the case of Portugal that has the Quota System in the Public Administration since 2001. However, in Portugal more than 10 years after the creation of this law, the public sector has less than 1% of disabled workers. The literature suggests that affirmative action measures, and specifically the quota system, are very controversial. However when the target group of these measures are disabled people, studies show that this measure gathers more consensus among non-disabled people. But what do disabled people think about affirmative action laws targeting themselves? There is a lack of studies about the perspective of the disabled people about this issue. In this study, we aim to better understand how disabled people perceive these laws and regulations. We will present the results of an online survey targeting only people with physical disabilities (N=155) where we explore their position about these affirmative action measures and what factors explain the different perceptions about the law. The study has two main goals: (1) analyze if physically disabled people agree with affirmative action measures in general, and with the Portuguese quota law; (2) to explore what factors explain the different positions of disabled people about these measures (i) if stereotypes are a barrier to the enforcement of affirmative action measures; (ii) also, we want to explore how disabled people justify the system and the social inequalities; (iii) finally, we want to explore the idea that the more people express a Belief in a Just World, the less favorable they are regarding these laws.

***Comparative study of the determinants of the effectiveness of educational policies of inclusion in France and Cameroon from the point of view of teachers***

**Author(s):** Ernestine Ngo Melha, Institute for Research in the Sociology and Economics of Education (IREDU) - Université de Bourgogne - Pôle AAFE - Esplanade Erasme

**Abstract:**

Considering the fact that inclusive education is an international recommendation (UNESCO, (2008, 2006, 2000, 1994); Framework for Action on Education for All, (2000); Millennium Development Goals (2000), Convention on the Rights of Persons with Disabilities (2006) ) ,

educational policies , both in the countries of the North and those in the South , more or less clearly take into account the educational needs of certain groups including children with disabilities. Considering also that teachers appear as key role players in the success of inclusive education related to children with disabilities (Asrat Dagne (2013). ( Kabano , 2001); Bothma M. & al. (2000) , it is judicious to look at factors that determine , from the teachers point of views , the effectiveness of such policies that are imposed to them.

The model of planned behavior of Ajzen (1991), which is one of the psychological models used to study the determinants of behavior (beliefs, attitudes and intentions) of individuals (facing the adoption of a instruction, a habit, a change) is adapted and used as a theoretical model to study the data collected through questionnaires, multivariate analysis is used to test the research hypotheses.

This paper aims at presenting the results of a nearing completion research conducted in France and Cameroon.

## **PARALLEL SESSION D (SESSION IN ENGLISH) (2<sup>ND</sup> FLOOR, ROOM 5)**

### **Disability rights and the UN Convention / Os direitos das pessoas com deficiência e a Convenção das Nações Unidas**

#### ***Disability Rights Monitoring "The way to a more just society and social change?!"***

**Author(s):**Elisa Fiala, PhD student at ISCS

#### **Abstract:**

Based on the assumption that the "changes that will make a better society for people with disabilities to live in will make a better society for everybody to live in" (Sutherland 1981, p.12), the presentation is going to outline that disability rights monitoring offers a tool to critically engage in disability studies. Focusing on my current research project that is based on an empirical research design and on emancipatory research methods, I am going to provide an insight into the possibilities of disability rights monitoring. Within the study, Article 27, the right to work and employment, enshrined in the UN Convention is monitored within the German and Portuguese context. The aim of the research is to provide a critical, comprehensive and explanatory understanding of the human rights situation of persons with disabilities, to raise awareness about the issue and identify areas and structures for social action and transformative politics. Through the active involvement of people with disabilities and the acknowledgement of their individual experiences, human rights monitoring is giving

people with disabilities a voice – a task that can be very empowering for people with disabilities and their supporters to fight for more just structures (Pinto 2011). Monitoring disability rights also involves the monitoring of systems. Signatory governments of the CRPD have the obligation to translate the rights enshrined in the treaty into practice to affect the lives of people with disabilities in a positive way. The monitoring process remains an important instrument to enhance public awareness and empower people with disabilities. The cross cultural aspect of my study offers the possibility to draw inferences and identify further areas of action on the one side and provides the possibility for cross-cultural exchange on the other side. References: Pinto, Paula Campos(2011a). Monitoring disability rights: A holistic approach. In Lee Ann Bassler; Marcia Rioux & Melinda Jones (Eds.) Critical Perspectives on Human Rights and Disability Law (pp. 451-478). The Netherlands: Brill Publishers. Sutherland, Allan T. (1981). Disabled We Stand. London: Souvenir.

### ***UN Convention on the Rights of Persons with Disabilities in practice: underpinning ideology issues***

**Author(s):** Natascia Curto, Phd Student- Philosophy and Science of Education

#### **Abstract:**

The UN Convention on the Rights of Persons with Disabilities has been the main subject of a large amount of international literature. Seven years after the drawing up of this document, experts adhering to the rights-based approach cannot avoid sensing a distance between literature and the daily life of people with disabilities. Also thanks to the work of disabled people's organizations, the separation between the rights which are sanctioned and the ones that are effectively enforceable is often stressed.

This paper offers and discusses two experiences of practical application of the UN Convention conducted by a research team between 2010 and 2013. The aim of the article is not to describe the experiences in details, rather than trying to show through these experiences how underpinning epistemology (and ideology) can affect the application of the UN Convention.

First, a practical application project referring to article 19 of the Convention ("Living independently and being included in the community") and will be used in this paper to reflect in particular on the disabling role of institutions and perpetuation of "special education" ideology in practice.

Second, the "Senza Muri" experience: a practical application project for article 8 ("Awareness-raising") that can tell something about what can actually be done to overcome the "specialty" ideology and promote a rights-based culture in the community.

Considering all these groundbreaking elements, there cannot be standard ways of implementing the Convention. It is unimaginable to come up with a list of a priori fixed actions, physical equivalent of the

Convention. Institutions and citizens must resort to their willingness to experiment, even before than to economic resources. Try out experiences, initiatives and paths keeping the Convention's cultural model as the reference point. These paths, involving all citizens, not just frail people, lead to the overcome of the challenge of inclusion.

### ***Our rights, our journey: Persons with disabilities speak out***

**Author(s):** Carlos Veiga (Minho University), Paula Campos Pinto (ISCSP, University of Lisbon), Diana Carolina Teixeira (ISCSP, University of Lisbon)

#### **Abstract:**

Article 33 of the UN Convention on the Rights of Persons with Disabilities specifically calls upon State Parties to establish a framework to monitor the implementation of the Convention. This paper is drawn out of a larger study that addresses the challenge of monitoring the Portuguese State compliance with the CRPD by conducting a holistic monitoring of the current status of disability law and policy, media representations and daily life experiences of persons with disabilities in Portugal. In this paper, we will focus on the analysis of the human rights experiences of persons with disabilities.

Sixty semi-structured interviews were conducted in three different regions of Portugal, allowing an examination of situations of inclusion or discrimination faced by persons with disabilities, aged 12 and over, across eight domains (family life, work, education, social participation, income security, health and rehabilitation, information and communication, access to justice). This approach enabled participants to select the topics they wanted to address. Interviews were transcribed and analysed with the qualitative analysis software NVivo in order to capture the realization or denial of human rights principles in the experiences reported by the participants, according to five human rights principles: autonomy, dignity, inclusion, participation and accessibility, equality and non-discrimination, and respect for difference. In all the research process, a participatory approach was followed, promoting the active involvement of persons with disabilities and their organizations in all phases of the research.

In this paper we will examine the meaning, context, and processes involved in the human rights experiences of people with disabilities. Identifying the gaps that exist between rights in principle and in practice, we will offer an understanding of the key obstacles and critical areas for the realization of human rights of persons with disabilities in Portugal.

***Political participation of people with disabilities in Austria and from a comparative perspective***

**Author(s):** Angela Wegscheider, Johannes Kepler University Linz / Department of social policy and politics

**Abstract:**

The proposed paper refers to article 29 of the United Nations Convention on the Rights of Persons with Disabilities and focuses on recent developments and the current situation of the participation in political and public life of people with disabilities in Austria and in comparison with other EU member countries. The results are mainly extracted of the author's research as well as her work for a recent ANED report and emphasise on the evaluation of the access to electoral rights and to voting processes, as well as scrutinizes organisations that advocate people with disabilities. The evaluation of the legislative regulation as well as their practical implementation shows that people with disabilities are deprived of their political participation by inaccessible voting environments and obstacles such as social barriers and a systematic lack of political representation. Firstly, inadequate regulations as well as a lack of consciousness from the administration promote inaccessible voting processes in Austria. On this point, with the help of a recent ANED report the Austrian situation is placed in relationship with other European countries. Secondly, the results reveals that next to Disabled People's Organisations very often and with an increasingly dynamic service providers for care or housing represent and speak for people with disabilities on a political level in Austria, which is not conform to Article 29.

**Parallel Session E (Sessão em Português / Session in Portuguese) (2<sup>nd</sup> Floor, room 7)**

**Inclusão e Qualidade de Vida/ Inclusion and Quality of Life**

***Inclusion and quality of life in children with special educational needs: representations and expectations of family***

**Author(s):** Natércia Caetano

**Abstract:**

This proposal summary communication is to present a study. The purpose of this study is to understand the concept of quality of live in children with special needs, according to parents

perception, with the title “Inclusion and quality of life in children with special educational needs: representations and expectations of family”.

This is a qualitative case study. The sample of this study are five families of children with special needs. All the children aged between 3 and 6 years old, and attend public schools in Silves, Algarve, Portugal. The instrument used for collecting data is a semi structured interview. This study therefore aims to give voice to parents with children with special educational needs and prepare a contribution in the current discussion on the forms of intervention in order to improve the quality of life of children, in the sense that they can fully develop their potential, in an inclusive society.

### ***Contribution of vocational rehabilitation system to (re)learn to live with acquired disability***

**Author(s):** Benedita Lima, Instituto de Educação da Universidade de Lisboa

#### **Abstract:**

The sudden beginning of a disability constitutes a turning point in individual biographical trajectories, yielding processes marked by a deeply learning dimension.

While it may present itself in many ways, disability in general and acquired in particular, always means some sort of limitation, increased by the negative and stigmatizing view of society, which influences the way people see themselves and get involved in community life. These circumstance have motivated the implementation of policies aimed the facilitating of social inclusion and participation of disability people, such as vocational rehabilitation measures.

However, despite the intervention models and public policy measures advocating the inclusion principle, the practice of vocational rehabilitation have been developed predominantly on the margins of the regular training system, and little is known about how they contribute to the reconstruction of life pathways of people with acquired disabilities.

In this paper we intend to analyze the role played by the Portuguese vocational rehabilitation system in the reconfiguration of professional biographies, giving voice to both institutional actors and people with acquired disabilities.

To achieve this goal, 6 semi-directive interviews with institutional interlocutors and 21 people with acquired disability were performed.

The analysis allows us to conclude that the system is mostly directed to people with birth disabilities and mental/cognitive disorders. It provides predominantly initial training, leaving out people with acquired disabilities, who mainly have neuro-musculoskeletal problems, forcing them to construct alternative ways, not necessarily more inclusive.

### ***The medicalization of education debate***

**Author(s):** Rosa Nunes, CIIE - Centro de Investigação e Intervenção Educativas and Teresa Gonçalves - Instituto Politécnico de Viana do Castelo

#### **Abstract:**

The group for the "Study and Intervention in Medicalization of Education", hosted at the Faculty of Psychology and Educational Sciences of the University of Porto, stems from concerns raised in today's world with the return and the increasing of biologist and geneticist perspectives in education. These perspectives elude the difficulties to educational responding to the challenges of a democratic school, where the collective action should be experienced as transformation project.

Labels and classifications, masked as diagnosis, are justifying the abuse of pharmacological prescription. It is alarming the number of children and adolescents treated for "attention deficit / hyperactivity disorder " with "oppositional defiant disorder ", the famous ODD, and many others. Medicalization is envisaged as the process that artificially turns non-medical issues into medical problems. Because these issues require an interdisciplinary approach, this open and multidisciplinary group aims at facilitating the replication of this ethical concern in training spaces, raising the understanding and awareness of the phenomena involved and the inherent enlightened intervention.

Following the launching of a manifesto on this theme (<http://educationmedicalisation.blogspot.pt/>) that was signed and commented internationally (many citizens connected to Forums and structures of international education and health as the World Education Forum, Movimientos de Renovación Pedagógica, Movimento da Escola Moderna), this communication has the aim to broaden the debate and awareness of the problems involved, to all those who share these concerns - parents, psychologists, professionals in education and health.

### ***Disability-oriented services in Algiers: Service (dis)articulation and its implication for the social inclusion of persons with disabilities***

**Author(s):** Albino Cunha, Paula Campos Pinto and Teresa Pinto, ISCSP - University of Lisbon

#### **Abstract:**

In a moment when Algeria is at a crossroads, facing pressure to couple its significant economic growth with a comparable social development, significant obstacles to the social inclusion of persons with disabilities have been systematically reported, an issue that has become especially pressing following Algeria's ratification of the CRPD in 2006. This study, led by a

team of researchers and civil society organizations from Portugal, Algeria and Canada, aims to understand the factors that hinder or facilitate the social inclusion of persons with disabilities in the wilaya of Algiers. To achieve this, the study draws on the paradigm of emancipatory disability research and the social model of disability .

This paper will present and discuss the results of a study on the articulation and complementarity of disability-oriented services in Algiers, paying special attention to the health, education and employment sectors. A series of interviews with relevant stakeholders, namely representatives from public offices (policy-makers and service providers), disability rights organizations and the users themselves – persons with disabilities – will be integrated with data from a documentary analysis of legislation and other political documents, to provide a global picture of the articulation and complementarity of disability-oriented services in Algiers. Obstacles to service coordination, access and efficiency will be presented and discussed, together with their implications to disability-policy design and assessment in Algeria.

# 4 July

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## PARALLEL SESSION A.3

### Disability, policy and politics / Deficiência e políticas públicas

#### ***Indigenous epistemologies of inclusive education and implications for children with disabilities and their families in India***

**Author(s):** Shridevi Rao, The College of New Jersey

#### **Abstract:**

The increasing globalization of educational practices has resulted in a steady transfer of educational policies and practices from the developed countries to the developing world. International development agencies, functioning within a post-colonial rubric of Education For All, have created standards for policies and practices in disability services and inclusive education for children with disabilities which are based on current trends in the developed world and meant for application in the developing world without consideration of local historical, political and socio-economic contexts. Referring to this as “the geodisability framework” (Campbell, 2009), scholars have pointed to an “epistemological disengagement” (Grech, 2011) whereby both material and human and differences in beliefs and attitudes towards disability are bypassed or overlooked. This presentation examines the following questions: How relevant is the universal template of inclusive education for individuals with disabilities, in developing countries with different local, historical, and social contexts? To what extent does it truly provide access to all children in developing countries? What new quandaries does it create? What local, cultural, and indigenous beliefs or practices does it overlook or obscure? What are the implications of this “epistemological silencing” (Grech, 2011) for children with disabilities and their families. The presentation focuses on the indigenous epistemologies of inclusion and community that are obscured in the push to impose westernized frameworks of inclusive education. Drawing on ethnographic studies and scholarship in the area of disability studies in education, the presentation identifies indigenous and local concepts of community and inclusion and underscores the importance of harnessing local understandings of community and inclusion in developing inclusive practices and policies. The presentation will utilize the “geodisability framework” and conceptual lenses drawn from the field of disability studies and disability studies in education.

## **Integration or inclusion**

### ***Access to rehabilitation services in Bogotá, Colombia. An opinion of different social actors***

**Author(s):** Marisol Moreno, Universidad Nacional de Colombia, (Colombia); Amparo Mogollón, Universidad del Rosario (Colombia); Nancy Molina, Universidad Nacional de Colombia (Colombia); Paola Balanta, Universidad del Rosario, (Colombia); Janeth Hernández, Universidad del Rosario (Colombia) and Claudia Rojas, Universidad Nacional de Colombia (Colombia).

**Abstract: Background:** Colombia radically reformed its healthcare system in 1993. The system is characterized by gross inequalities in the continuum of rehabilitation care utilization with poor solutions to the needs of people living with disabilities.

**Methods:** We carried out an exploratory, descriptive-interpretative qualitative study conducting 18 individual semi-structured interviews and six focus group. A theoretical sample included: managers, providers, rehabilitation professionals, professors, users, and caregivers. Narrative content analysis -segmented by cases, informants and themes- was conducted using Atlas-ti. Established categories for analysis were: concept of access to rehabilitation and factors that influence access.

**Results:** We found three perspectives on the concept of access: functionalist, based on social inclusion, and built on right to self-determination and citizenship. The following factors influencing access to rehabilitation were identified: 1) contextual factors were poverty and armed conflict. These factors have policy implications because public services are limited to victims, excluding other populations of people living with disabilities. 2) Public policy factors were an emphasis on disability and not in the organization and delivery of comprehensive rehabilitation services and a lack of integration of private and public resources. 3) The institutional factors were divided on insurers and rehabilitation care provider's factors. The insurers' factors were: Use of mechanisms for cost reduction, fragmented contracting and authorizations delay rehabilitation care. The provider's factors were: poor quality of care, insufficient resources, low response capacity, lack of coordination across different levels of rehabilitation care and limited geographical accessibility. Finally, 4) the factor identified by most users, hindering their access to rehabilitation services, is their economic situation.

**Conclusion:** Different social actors identified contextual, public policy, institutional and users' access barriers to comprehensive rehabilitation services. Effective government action is required to ensure the right to rehabilitation care and an effective response to the needs of people living with disabilities.

## ***Fostering the production of Assistive Technology in Europe? A multidisciplinary analysis***

**Author(s):** Delia Ferri, LL.M., Ph.D. Centre for Disability Law and Policy –National University of Ireland Galway

### **Abstract:**

Assistive Technology encompasses all the practical tools that support functional needs of people who experience difficulties linked to disability or ageing, from walking frames, wheelchairs, and hearing aids, to computer-based communication aids and voice activated mechanisms.

Within the field of disability studies there is a growing attention to assistive technology and their effects. Researchers, policymakers and advocates often underline their relevance and positive effects as tool to allow people with disabilities to enjoy their rights, although some academics hold a more ambivalent attitude towards the field.

The European Union (EU) seems to embrace the view that assistive technology enables more persons with disabilities than ever before to communicate, participate in society, and in the economy. Thus, the EU is attempting to foster the research and development of new and more efficient assistive technology through financing research projects aimed at developing new high tech assistive devices. The EU has also allowed Member States to provide subsidies to national firms developing and producing these devices via State aid regulation.

This paper explores the EU policy decisions in this field, and contrasts it with the experience of people with disabilities as recipients of assistive technologies as obtained through a series of semi-structured interviews.

The paper will merge a legal and policy analysis together with qualitative data emerging from the interview. Through this research a better understanding may be reached on how the development of assistive technology can contribute to the enjoyment of human rights, and how the EU can better meet the need of people with disabilities through its state aid and research policies.

## Parallel Session F

### Theoretical and methodological developments on disability / Novas abordagens teóricas e conceptuais em torno da deficiência

#### ***Social postures and disability***

**Author(s):** Weislo Emmanuel, Synoos

#### **Abstract:**

How to understand ambivalence about disability in us, often despite us, between a share of shameful rejection and the desire for a full social participation for persons with disabilities?

A common reading of the link between societies and disability suggests a linear development from elimination to participation, passing through different stages. Searching a more anthropological perspective yet brings up that the difficulties faced by people with disabilities exceed the simple evolution of mentalities and political options. More in depth, one can observe the relationship to disability in our modern societies through six « social postures », fundamental and significant, having strongly impregnated practices: elimination, sanction, donation, segregation, solidarity and inclusion.

The research shows that these postures are all at work in the modern world, and that it is impossible to understand the issues surrounding the place of persons with disabilities regardless of this data. The most immediate effect of the co-presence (and competition) of these postures in the relationship to disability is to keep individuals in a liminal status. This « in between » status can be understood as an effect of persistent ambiguities, when for example, it is sometimes impossible to choose between "appropriate support" and "access to mainstream facilities" in a satisfactory manner.

While it is essential to promote a society open to all, a certain ideology of social participation advocating total deinstitutionalization can become counterproductive by refusing to take into account the particularity of the different or local situations. The approach of disability through the game between «social postures» invites to an ethic of responsibility taking into account the ambivalences and paradoxes that today still surround the situation of handicap.

## ***Inclusive Development as Crip(dys)topic Promise: Querying Development, Dis/ability and Human Rights***

**Author(s):** Isabelle Garde, University of Vienna

### **Abstract:**

The demand to include people with disabilities into development policies and projects as articulated by activists, international organizations and development NGOs as well as within the UN Convention on the Rights of People with Disabilities (UNCRPD) points to a desire for a more just future. This paper asks if and how, “inclusive development” leads to a querying of ableist norms and processes of exclusion within practices and discourses of “development”. By looking at disability knowledge produced within the discourse on inclusive development and the ways in which ableist and colonial dichotomies are re-installed within the epistemologies of ‘inclusive development’, I examine the simultaneity of empowerment and re-colonisation, of inclusion and exclusion that lie at the heart of inclusive development. Thus, I argue that the promises of justice and inclusion produced within development discourse point to a future that is always already out of place. Revealing this crip(dys)topic future called forth within development discourses opens up space to reconsider projects of justice from a critical crip positionality.

## **Narrative Production: methods to create collaborative research with people with functional diversity**

**Author(s):** Pamela Gutiérrez, Occupational Therapy School, University of Chile

### **Abstract:**

The narrative productions seeking joint development between researcher and participants in a situated understanding about the dilemmas and / or research questions. Allowing, through a relationship / localized / or dialogue, emerging knowledge, validate and connect with the research process, a knowledge valued in itself , not to be used , but to contribute to the problem of diffraction investigation (Balasch , Callen , & Montenegro, 2004).

The narrative productions refer, first, to the desire to produce an organized narrative, which hardly occur in in-depth interviews or narrow transcription of interviews or conversations (Balasch & Montenegro, 2003). Second, the textualization can adequately express the notion of product, as in the preparation process have deepened and jointly analyzed the ideas expressed in the narrative , avoiding the presentation of them as discursive data or records to be analyzed. And Thirdly and finally , the joint development will generate a valid for the

audience that is targeted text, a text that will serve the research objectives and the objectives of the participant, allowing the participant / author herself appears in the report research and can talk directly as other authors in the text ( Balasch & Montenegro, 2003).

This methodology departs from the narrative interview, he understands the position of the researcher (interviewer) as a passive listener, who must not comment or intervene in the production of the "data" (Flick , 2004). The narrative productions are presented as a methodology that allows the co - construction of knowledge, which is especially important in people with functional diversity or disability, who have been systematically considered from the logical traditions of knowledge production, as recipients and non-producers of knowledge.

***Rehabilitation for empowerment: an anthropological study of physically disabled persons in Southeast Nigeria***

**Author(s):** Okechukwu Vincent Nwokorie, PhD Programme in Social and Cultural Anthropology, KU Leuven, Belgium

**Abstract:**

Disability is a stigmatising, transcultural and universal human experience which evokes empathy. Rehabilitation is a global term for various forms of interventions aimed improving the living condition of the disabled often resulting in social inclusion and autonomy over life choices, otherwise known as empowerment. Also in Nigeria rehabilitation and empowerment have gained purchase in the imagination of policy makers, politicians, development experts and the general public as solution to social exclusion of disabled people. Given that about 19 million people are living with a disability, there has not been any systematic study on the processes of rehabilitation of disabled people, especially in relation to the role of education and empowerment as strategies for rehabilitation, and Nigeria's approach to the UN Convention on the rights of persons with disability. To better understand how Nigeria governs its space of disability, a research is needed on the processes of rehabilitation of disabled people. The study will also enable to understand the everyday experiences of disability, and some of the constraints they face, as well as make the best assurance for good policies and services for disabled people. The aim of this study is to investigate ethnographically and in-depth the process of rehabilitation of wheelchair users in Southeast Nigeria. Through 12 months of field research in Nigeria, I shall conduct ethnographic fieldwork (participant observations, interviews) at Hopeville Rehabilitation Centre, Uturu, Abia state, Southeastern Nigeria. There is a limitation in this study. This research is based on data on people with physical disability of the lower limb/s. No attempt is made to generalise to other categories of disability.

## Parallel Session G

### Gender, sexuality and embodied experiences / Género, sexualidade e experiências de encorporamento

#### ***Self-determination and the exercise of sexual rights: an emergent need for the applicability of the United Nations Convention on the Rights of Persons with Disabilities***

**Author(s):** Lilia Virginia García, Escuela de Medicina y Ciencias de la Salud Universidad del Rosario. Bogotá/ Colombia

#### **Abstract:**

**Background:** Persons with Intellectual disability (PID) have been historically excluded from information and educational issues on Sexuality, and Sexual and Reproductive Rights (SRHR), although they are part of the holistic development of every individual from the Human Rights perspective. As a consequence of lack of education, clinical approaches and segregated models, the vulnerability of this population in terms of sexual abuse, gender violence and sexual transmitted diseases among others, acquires a public health problem dimension worldwide. New challenges for sexuality programs and services and educative interventions emerge, as the result of the citizenship status and legal capacity recognition for this population. **Objectives:** To advance towards the understanding on prevalent stereotypes about PID sexuality, and sexual and Reproductive Rights, issued from different sectors and social actors in Bogotá Colombia, and the prevalent institutional, professional and parental practices around them. **Methodology:** A qualitative study based on an intentional and social representative sample of 15 focus groups. The information was recorded and systematized using software AtlasTi 6.0. The results were analyzed and interpreted according to the described categories with triangulation of the information. **Results:** Sexuality stereotypes of PID were identified in all groups, as the result of a prevalent clinical model, which assumes deviant and pathological manifestations on this group. Although some rights on SRHR are recognized, the majority of groups, revealed doubts about the PID capacity to their exercise, particularly the Reproductive Rights. Self-determination emerges as a fundamental issue to be addressed as a transversal topic on educational programs in order to promote opportunities to exert their sexual rights. **Conclusions:** The study reveals the average misinformation on this topic, and the crucial need to implement public educative policies. The traditional approaches on sexuality education under a prevalent biologicistic scope, remains limited to face the demands of the Convention for the exercise of legal capacity and self-determination of this population.

### ***When disability rights and feminist claims meet: some examples of political contentious in Spain***

**Author(s):** Míriam Arenas-Conejo, PhD student in Sociology at the University of Barcelona & Research Assistant at the Universitat Oberta de Catalunya

#### **Abstract:**

The feminist and disability rights political agendas share several concerns. For example, both seek at making the personal into the political, and fighting against a history of oppression based on biological instances (be it sex and/or impairment). Nevertheless, there are also some contentious topics between both social movements. It is the case of reproductive rights (on eugenics and abortion), conceptualizing gender violence, or designing care policies, among other.

This presentation is aimed at introducing some of these splits and synergies between both political agendas, situating them in relation to the public debates arisen in Spain, during some legislative drafting processes. It is the case of the already passed laws about gender violence (2004) and social care (2006), as well as the current contentions around the reform of the abortion law and the regulation of sexual assistance for disabled people.

At the crossroads of both agendas, disabled women (and her allies) are struggling to overcome these conflicts, by generating new discourses based on their intersectional experience and introducing them in both social movements. However, their voices (especially those with a feminist approach) still remain rather marginalized in the Spanish public debates.

### ***The pleasure principle: body, disability and sexuality***

**Author(s):** Bruno Sena Martins, Ana Cristina Santos and Ana Lúcia Santos, Centre for Social Studies, University of Coimbra

#### **Abstract:**

Despite transformative laws and policies, the lives of disabled people are still marked by exclusion, poverty and prejudice. Within this group, disabled women are in a particularly vulnerable position, accumulating the inequalities based on disablism and sexism. Focusing on the sexualities of disabled women we aim at exploring the embodied character of experience considering the consequences of this simple fact: our bodies are not only objectified with cultural significances, they are also a condition for our existence in the world and in culture. Through our bodies we gain access to the world, and to others. Bodies feel pain, pleasure, suffer disease and violence and, as Judith Butler (1993: xi) argues, nothing of this can be

demobilized as mere representation. Notwithstanding, the materiality of bodies – and of our own corporality – is always presented to us embedded in a scheme of intelligibility. Therefore, cultural values in debate over the body do not invent it, but participate instead in its ‘materialization’, the practice of creation and reiteration by which the body matter gains sense (Butler, 1993: 14-15). It is through these schemes of intelligibility that aesthetic models and sexual practices are recursively enacted. From the experiences and voices of disabled women, I will explore the relation between representation, embodied experience and sexual pleasure.

### **Parallel Session H.1 (Session in English)**

#### **Quality of life and social participation / Qualidade de vida e participação social**

##### ***Residential choices of persons with disabilities: which are the constraints and trade-offs?***

**Author(s):** Gwenaëlle Raton and Aline Alauzet, Ifsttar/TS2/Lescot, Lyon, France

##### **Abstract:**

For any individual, the residential choice is an arduous task which results from trade-offs between personal wishes, complexity of the housing market and constraints on individual or household. Housing choice is the subject of many researches, but residential choices of persons with physical, mental, sensory, cognitive or intellectual disabilities are rarely studied. Finding adapted housing allowing independent living increases the complexity of the task. More generally, which are the constraints the persons with disabilities have to face for their residential choices? How is the decision made?

This communication examines the decision-making process involved in residential choice for persons with disabilities in Lyon (France). Qualitative interviews were conducted with persons with various disabilities, various origins of disability (present from birth or acquired), and various family and employment status.

Results show that constraints on residential choice are strong for people with disabilities, whatever their impairment. These often have to face discrimination and inequalities (for example for access to credit and insurance). In addition, lack of social integration can limit access to housing market information. Accessible house can be very expensive while a part of persons with disabilities have low-income, mainly coming from allowance, and trade-offs have

to be made between different components of the personal life: personal impairment, income, interpersonal relationships and geographical characteristics.

There are specific housing locations preferences for people with disabilities depending on the environment ability to encourage activity or hinder a person's ability to be active. We also show that trade-offs are made between welfare in the house (adapted housing) and locational preferences in the city (accessibility to urban amenities). These preferences and trade-offs can differ depending on the nature of disability.

This work is part of a larger project about multiple mobility inequalities, funded via the "Mobility and Inequalities" research axis of the PST Rhône-Alpes (community of French researchers on the topic of mobility of people and goods).

### ***Disability and Purchasing Power: A Global Perspective***

**Author(s):** Robert Huffaker, Marie Curie Research Fellow at Fundosa Technosite, S.A.

#### **Abstract:**

The role of people with disabilities and the digital divide is a subject that is investigated thoroughly, however many ICT companies are still not making their devices accessible to people with disabilities and are losing out a large amount of potential market share. This paper will identify the purchasing power of people with disabilities not just throughout the EU28 but also in low and middle income countries and will examine what companies experience to be the barriers to making their goods and services accessible by using secondary resources and desk research. The roles of legislation such as the upcoming European Accessibility Act and of public procurement need to be examined in order to show how people with disabilities can be active market participants. In conclusion, this paper provides background to the current state of affairs of eAccessibility and its pertinent business case, and gives best examples that show how businesses can implement accessible practices and increase their market share.

### ***The Impact of Childhood Disability on Maternal Labour Market Outcomes in Ireland***

**Author(s):** Áine Roddy and John Cullinan, School of Business & Economics, National University of Ireland, Galway, Ireland.

#### **Abstract:**

This paper investigates the impact of childhood disability on maternal labour market outcomes. Using data from the first wave of the 9-year-old cohort of the national Growing Up in Ireland survey, we examine the association between a child's disability status and a range of maternal labour supply measures including labour force participation, turning down work

activities because of family responsibilities and weekly hours worked. In addition, a societal dimension is considered by examining how the adequacy of special resources in schools impacts on labour force participation for mothers of children with disabilities. Overall the results suggest that mothers caring for a child with a disability are less likely to be participating in the labour force, are more likely to turn down work opportunities and, in some cases, work fewer hours. Furthermore, mothers who have a child with a disability and who are participating in the labour force are significantly more likely to rank the adequacy of special resources in their child's school as poor in comparison to mothers who have a child with a disability and who are not participating in the labour force. These results are considered within the context of the interplay between childhood disability and societal factors that determine the burden of care. Implications for public policy include the need to address these disadvantages by formulating policies that provide appropriate supports and services.

***Barriers to inclusion in primary education for children with disabilities in Zimbabwe***

**Author(s):** Marcella Deluca, Carlo Tramontano and Maria Kett, Leonard Cheshire Disability & Inclusive Development Centre - Department of Epidemiology and Public Health - University College London

**Abstract:**

This paper presents findings from a study undertaken at the start of a three-year research project to examine current policy, practices and service provision of inclusive education (IE) in Zimbabwe. The results of the research will contribute to the limited literature examining knowledge, attitudes and practices of teachers and families around IE. The research highlights the barriers to effective implementation, as well as provides evidence-based results that facilitate programme adaptation according to identified need. The findings presented here are from a desk-based review of current policies and practices regarding disability and education in Zimbabwe; school-level information gathered on girls and boys with disabilities in four districts in Mashonaland West Province (MWP); as well as results from an initial survey on knowledge, attitudes and practices of parents or caregivers, teachers and head teachers around inclusive education. Major findings highlighted a lack of specific training in special education needs and/or IE by teachers or head teachers, and a predominance of children with 'learning difficulties'.

This research is part of a three-year programme led by Leonard Cheshire Disability Zimbabwe Trust to promote the provision of inclusive primary education for children with disabilities in MWP. The overall outcomes of the programme will enable a better understanding of the factors which contribute to improved and increased participation of children with disabilities

(enrolment, retention and accessibility) in primary education as a result of the programme; the attitudes of families towards the education of children with disabilities; learning from evidence about what policies and practices have the best results in the context in Zimbabwe and use this evidence to both improve quality of education for children with disabilities and to inform policy from good practice as well as sharing best practice and lesson learning with stakeholders and government to improve awareness, capacity, and service provision.

## Parallel Session H.2

### Disability representations and discourses

#### ***Media Representations of Disability: How are people with disabilities perceived by society?***

**Author(s):** Maria João Cunha and Paula Campos Pinto - ISCSP, University of Lisbon

#### **Abstract:**

Article 33 of the UN Convention on the Rights of Persons with Disabilities specifically calls upon State Parties to establish a framework to monitor the implementation of the Convention. This paper is drawn out of a larger study that addresses the challenge of monitoring the Portuguese State compliance with the CRPD by conducting a holistic monitoring of the current status of disability law and policy, media representations and daily life experiences of persons with disabilities in Portugal. In this paper, we will present and discuss the results of a study of social representations of disability and disabled people found through media analyses.

How are people with disabilities perceived in society and how do they perceive themselves is highly influenced by the ways in which they are portrayed in the media. To conduct this analysis we selected three of the most important print media outlets in terms of audiences in Portugal and surveyed all the published articles that addressed the subject of disability over the last five years (from 2009 until 2013). Quantitative analyses were conducted to determine different dimensions: a) news variables, such as number of articles, their placement, highlight, type, news dimension and disability prominence; b) disability variables, such as disability types covered in the news and main topics covered, disability information sources and main voices in the news; and c) media awareness on the Convention on the Rights of Persons with Disabilities as well as framing mechanisms. Qualitative assessments were also conducted on sampled articles to examine specific features in media discourses that enabled and constructed news

framing. Implications of these results will be discussed as a key dimension to understand the current rights situation of persons with disabilities in Portugal.

***Deaf people as representations of disorder: A study of representations of Deaf people in medical discourses of the 19th century***

**Author(s):** Mathilde Villechevrolle, Laboratoire Sens et Compréhension du Monde Contemporain (LASCO) – University Paris Descartes / Institute of Mines-Télécom

**Abstract:**

Medicine, as the science of the body wants to explain how the body works: it must then represent and render visible the invisible, the inaccessible interiority of the living body. In this sense, it draws from what Judith Schlanger has called the “discursive knowledge”, that is, a discourse that expresses outcomes in words. Since Antiquity, doctors have not ceased producing knowledge with the support of analogies and images. The birth of otology and the controversies around oralism, as a pedagogical and curative approach, have given way to an abundant literature about deafness in which representations of the Deaf have emerged that still feed contemporary imagination. The Deaf have been described as idiots, savages, naïves, superficial, perverse, lazy, machiavelic, aggressive, proud, cruel, etc. This list is not concerned with rationality: Deaf people may appear at once as excited and lymphatic, astute but manipulable, empowered and powerless. Through the analysis of a body of medical texts, published throughout the 19<sup>th</sup> century, we seek to show the link between social representations of the Deaf and the medical metaphors that translate the functioning – or better said, disfunctioning – of Deaf bodies. If we can find there the three-fold nature of abnormality – monster, masturbator and incorrigible – which Michel Foucault has highlighted, this literature enables us to understand abnormality and its representations in terms of excess. The body thus becomes a true political and social entity which emphasizes the ideal of democratic functioning.

***Gutta and the “Dahomey Amazons”: Colonial spectacles of gender, race and bodily otherness in 1890's Central Europe***

**Author(s):** Filip Herza, Department of Anthropology, Charles University in Prague

**Abstract:**

Tracing the visit of a group of so-called “Amazons of Dahomey” in Prague in 1892, the paper interrogates the history of representations of race and body within the colonial context of 19th

Century Central Europe. As the members from different non-European nations appeared within the freakshow culture, performing on stage alongside other “human marvels”, such as the “conjoined twins” or “lilliputians”, this paper urges for critical appreciation of the interplay between race, gender and bodily difference that sustained the colonial ideology of the exotic “other” as well as the notion of normative body of Euro-American individual. Focusing on one particular case – the death, burial and the after-life of Gutta, the “Dahomey Amazon warrior” in 1892 Prague – the paper analyses different imaginations of race, gender and bodily difference in popular culture of the time, as well as the agency and self-fashioning of the performers who often became “professional savages”, cunningly responding to the expectations of their audience.

## **Parallel Session I (Session in English)**

### **Quality of life and social participation/ Qualidade de vida e participação social**

#### ***Escala Pessoal de Resultados: a Portuguese Quality of Life Scale for Adults with Intellectual Disabilities***

**Author(s):** Cristina Simões, Faculty of Human Kinetics, University of Lisbon and Sofia Santos, Center for the Study of Special Education, Department of Education, Social Sciences and Humanities, Faculty of Human Kinetics

#### **Abstract:**

Assessing the Quality of life (QOL) for people with Intellectual Disability (ID) have recently became a major emphasis in research because this concept is essential for intervention with this population. In Portuguese services, it is crucial development, implementation and use a systematic approach to the assessment of core QOL domains. In Portugal, specific instruments are required to assess QOL in people with ID. Hence, it is necessary to develop a scale that allows self-reported measures to gather information about their subjective perspectives and goals. This study aims to analyse the reliability and validity of Escala Pessoal de Resultados (EPR), the Portuguese version of Personal Outcomes Scale (POS) (Loon et al., 2008).

After the cross-cultural adaptation, the EPR was re-administered to same person and proxy at 2-3 weeks following its first application. The reliability of the scale was analyzed by Cronbach’s alpha, split-half, test-retest and inter-rater coefficients. We also performed content validity,

concurrent validity and construct validity. The final sample included 1264 adults with ID (intermittent and limited support needs), and respective proxies.

The EPR showed an excellent internal consistency in self-report ( $\alpha=.88$ ), in report of others ( $\alpha=.90$ ) and for both parts ( $\alpha=.94$ ). Test-retest scores ranged from .89 (self-report) to .92 (report of others), and inter-rater of domains ranged from .31 to .85. In addition, the scale showed adequate scores concerning to validity indexes. These psychometric characteristics introduced the EPR as a useful measure of personal outcomes scales for Portuguese adults with ID. EPR is an important tool to improve program services and support planning, based on self-report and report of others ratings. Also gives to Portuguese rehabilitation services QOL indicators that should be included in interventions, the opportunity to know individual needs and improve a multiple dimensions of a person's life.

#### **References:**

Loon, J., Hove, G., Schalock, R., & Claes, C. (2008). Personal Outcomes Scale: A scale to assess an individual's quality of life. Gent: Stichting Arduin.

#### ***New tools for education. The example of a French autonomy-based device for students with disabilities***

**Author(s):** Cristina Popescu, Institut national supérieur de formation et de recherche pour l'éducation des jeunes handicapés et les enseignements adaptés<sup>1</sup> (INSHEA), GRHAPES, Paris, France

#### **Abstract:**

Since 2005, the French law encourages the inclusion of students with disabilities within the mainstream school. Therefore technical and human assistance might be given to these students in order to better fulfil their learning activities. This presentation will consequently describe the manner in which new technologies influence the practises of the young people with disabilities within the political context we previously mentionned. More precisely, the transformations brought by an experimental device developed in France in order to help its users within their note taking and knowledge management activities will be underlined. And most importantly, the new place of digital technologies within the social model of disability that claims an universal design<sup>2</sup> is among the main questions addressed within this work. The data collection procedure involves a document study and an ethnographical approach in a specific French educational environment. A variety of disability specialised learning professionals were thus met in different contexts, from informal discussions to group

presentations. Further, we will show how a new category of technical tools, the autonomy-centred ones, tend to be encouraged in comparison to some more old technologies, for instance the pedagogy-oriented ones. If the last kind of tools are more oriented towards the teacher's activity, the first ones we mentioned directly address to the students. Finally, we will underline how the equity of access to technology and its ease of usage are essential elements applying to the various impairments. However, it remains difficult to conceive an unique tool for all the users as the different needs can sometimes demand contradictory configurations.

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## **Enjoy the Difference: sharing experience in university apartments**

**Author(s):**Valentina Alessandria, Anthropologist - Senza Muri, association of social promotion - Torino – Italy; Federica Valsania, Anthropologist - Senza Muri, association of social promotion - Torino – Italy and Lucia Bertodatto, Psychologist, Torino – Italy

### **Abstract:**

Enjoy the Difference is a project born in Turin in 2011 from the collaboration of the University of Turin, City of Turin. Senza Muri Association and a students organization.

ETD provides apartments sharing opportunities for young college students of the University of Turin, regardless of field of and young people whit physical o sensory disability, in equal relationships. ETD offers the chance to live in a low cost flat and provides young people with disabilities the opportunity to share everyday life with their peers outside the family unit.

For all flat mates ETD is an opportunity to develop social skills within a mutual environment.

ETD promotes a new (in Italy) positive approach to disability, the foundation for a truly inclusive society!

Apartment sharing lasts for 12 months and begins in October. The living arrangements are: students are not the assistants of young people with disabilities, whom should have a good degree of autonomy or provide for their own external assistance.

The apartments are located in the city center. Flats will be shared between 2 girls and 2 boys, whom will be selected via motivational interviewing.

The project involves psychological supervision for each living nucleus, in which tenants discuss the home's community dynamics, relevant problems which should emerge from flat sharing, individual differences and the "role" of diversity based on their experience.

In conjunction with psychological supervision the project provides two additional support initiatives: training sessions with University teachers about the UN Convention and the importance of social capital, and a team of peer educators with disability who will establish informal relationships with the tenants, supporting them for the duration of the project.

In the project's third edition we aim to present the first results, strengths and what we need to improve.

### ***A portrait of the social inclusion of persons with disabilities in Algiers: Access to services and social representations of disability***

**Author(s):** Teresa Pinto, Paula Campos Pinto and Fausto Amaro – ISCS, University of Lisbon

#### **Abstract:**

At a moment when Algeria is at a crossroads, facing pressure to couple its significant economic growth with equitable social development, significant obstacles to the social inclusion of persons with disabilities have been systematically reported. This has become an especially pressing issue, following Algeria's ratification of the CRPD in 2006. This paper is part of a larger study, led by a team of researchers and civil society organizations from Portugal, Algeria and Canada, that aims to understand the factors that hinder or facilitate the social inclusion of persons with disabilities in the wilaya of Algiers.

Our paper will present preliminary results of the quantitative strand of the study. A questionnaire was used to assess a set of indicators in domains crucial to the social inclusion of persons with disabilities (i.e. access to healthcare, education, work, social and political participation, in addition to perceptions about the social representations of disability). This questionnaire was applied, first to a sample of 1000 households, randomly chosen among the 57 communes of Algiers, respecting socioeconomic and population density criteria, in accordance to the Politz Method. On the basis of this sample, the prevalence rate of disability in the region was estimated. Secondly, the same instrument was applied to persons with disabilities identified through local organizations, following a Quota Method, controlling for gender, age and disability type. Using these two procedures, a total sample of 300 persons with disability, aged 15-45, living in Algiers, were interviewed. In this presentation, preliminary

results of this survey will be presented and their implications to the analysis of the factors that sustain the social exclusion of persons with disabilities in Algiers will be discussed.

## Plenary Session 2

### Framing Social Identities and Participation

#### ***The UN Convention on the Rights of the Child for Children with IDD in Portugal***

**Author(s):** Sofia Santos e Fernando Gomes, Fac. Motricidade Humana, ULisboa

#### **Abstract:**

This article aims to monitor the implementation of the UN Convention on the Rights of the Child (CRC) from the perspective of children with intellectual disabilities, in Portugal. The study was initially developed within a larger international project financed by DAPHNE Programme of the European Commission that combined the expertise on intellectual disability and on children's rights of the project partners - Inclusion Europe, Eurochild and Faculty of Education - Charles University (Prague) and 23 European national experts. The goal is to present an overview of the situation in Portugal since 2001. Therefore, the report includes a critical analysis of the content and resources available in the last two national report to the Committee on the Rights of the Child as well as alternative reports by different NGOs (2001 and 2011) in five different areas: health, education, abuse, family and de-institutionalization, and promotion/participation of the child. Results showed that CRC implementation from the perspective of children with ID is far from satisfactory in all five areas. While some attention has been paid to education and health, the country should focus also on other areas such as abuse and participation of children with intellectual disability.

Portuguese legislators are aware of the rights established by the UN CRC, having equated and designed for this purpose a legislation package that intends to regulate the inclusion of children in their ecological context, even though there is an even greater need for better implementation and monitoring of such laws to everyday practice, which is the weakest aspect of the Portuguese national reports. The focus should be, now, on putting into practice all measures adopted by law, as well as the creation and application of a viable and reliable monitoring system in Portuguese context and stimulated more research in the area. Finally, were drawn some recommendations.

#### ***The Overpowering Role of Policies in Constructing Social Identities of Children with Disabilities***

**Author(s):** Maha Damaj, American University of Beirut

#### **Abstract:**

The research investigates the current Lebanese social policy and practices concerning disabled children in general and visually impaired children in particular on the social construction of

disabling identities. This is relevant to current national and global disability rights movements, which infrequently take children and their specific issues into consideration. It is particularly pertinent to Lebanon which passed its first rights-based disability law in 2000 and continues to struggle with its implementation.

This study was conducted through an organisational ethnography of a residential institution for children with severe visual impairments and was supplemented by interviews with the children, some members of their families, teachers, staff and alumni from the institution, as well as participant observation sessions at integrative settings, and interviews with parents and activists pursuing inclusion. The analysis focused on investigating the inclusionary versus exclusionary nature of policy and practice; the availability of mechanisms allowing for children's participation in these contexts; and the impact of these practices on the self-identities of disabled children. Theoretically, the analysis built on current literature in disability studies and the sociology of childhood, as well as drawing on Foucauldian ideas of power, control and surveillance and applying Goffman's concepts of stigma and the concept of a total institution. The findings show that rights based legislation cannot on its own result in inclusive changes of policy and practice. In the absence of implementation mechanisms, practices remain predominantly exclusionary, with no effective mechanisms for the meaningful participation of parents or children, eventually socialising the children into disabled identities. Children 8 - 12 years of age were not exhibiting any noticeable resistance to the systems of control, and had adopted the discriminatory values relating to disability exhibited around them.

### ***Transition to adulthood, regimes of inclusion and social participation***

**Author(s):** Serge Ebersold, INSHEA

#### **Abstract:**

Despite efforts made to improve their participation opportunities, youth with disabilities did not benefit to the same extent from increased growth and employment opportunities in the past decade and their improving access to higher education did not, for example, prevent them from being excluded from social roles and responsibilities youth access to such as employment, independent living, marriage, etc.,. Inequalities increased therefore in most OECD countries in terms of education, employment as well as poverty which is of great concern in view of the current jobs crisis which is likely to hit already vulnerable groups such as people with disability hardest . The presentation will describe transition opportunities to adulthood youth with disabilities have and analyze the mechanisms and rationales underpinning their pathways beyond secondary education. Building upon a research

implemented on transition to higher education and to employment in several OECD countries, it will highlight the social participation youth with disabilities have and investigate factors supporting or hindering them having the same opportunities than the general population, especially with respect to the coherence and the cohesion of their pathways. It will also focus on education systems' enabling effect and their ability to prevent them from being excluded by providing them with the needed skills, by empowering them to face new responsibilities and social roles and by supporting them to cope with transition issues. The comparative framework developed will allow relating youth with disabilities' transition opportunities to the enabling or disabling effect of the existing regimes of inclusion in participating countries.

***Self-determination and social participation: The impact of the inclusion of people with intellectual disabilities in the labour market.***

**Author(s):** Carlos Veloso da Veiga e Luísa Martins Fernandes, UMinho

**Abstract:**

Recognizing that the social participation of people with disabilities in society requires self-determined behaviour, in this communication we analyse the impact of professional inclusion in the performance of a set of personal autonomies. Among these autonomies we include self-care, exercise of various social roles and physical mobility, which are relevant in social participation and achievement of an autonomous life, with independence and quality of life. In particular, we present and discuss the results of a survey conducted with a sample of 36 people (19 men and 17 women) with mental disabilities included in the labour market after professional training.

Considering self-determination as a key agent of social participation, our research has shown that professional inclusion produced improvements in the quality of life of those surveyed, increasing their levels of autonomy and independence.

The research also highlighted the day-by-day factors that hamper professional inclusion from contributing to a better quality of life in terms of self-determination and independent living. These factors also show the existence of gender differences. The identified trends show that women participate less in collective life. When considering the distribution of opportunities for participation and the limiting factors on the exercise of self-determination, women are found to be less autonomous and independent.

Finally, the research allows us to recommend that professional training should be reoriented to produce both self-determined thinking and aspirations of an independent and participative lifestyle. The professional training must prepare individuals to be competent not only in the exercise of their future profession but also in their day-by-day life.