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Speakers' presentations

**EU DISABILITY LAW AND
THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH
DISABILITIES**

SEMINAR FOR POLICY PRACTITIONERS

Trier, 23-24 May 2016



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The UN CRPD: key features

An-Sofie Leenknecht, EDF Human Rights Officer,
European Academy of Law, Trier, 23 May 2016

EUROPEAN DISABILITY FORUM

- Represents 80 million persons with disabilities in Europe
- Organisation of persons with disabilities
- Umbrella organisation with national platforms and European federations
- Represents the diversity of persons with disabilities, including persons with intellectual and psychosocial disabilities
- Promotes the human rights of persons with disabilities at European Union & international level

THE EUROPEAN DISABILITY FORUM

- Mission → Guarantees Human Rights through an active participation of persons with disabilities
- Values → Human rights
Equal opportunities
Non-discrimination
Gender equality
- Vision → A society that includes persons with disabilities is a better society

THE EUROPEAN DISABILITY FORUM

- We make our voices heard at the level of the EU institutions
- We discuss with NGOs, industry and social partners
- We deliver the expertise of persons with disabilities to the EU decision makers
- On policy areas such as transport, ICT, social protection, employment, education, justice, fundamental rights and non-discrimination

OUTLINE

- The UN Convention on the Rights of persons with disabilities (UN CRPD) : timeline, purpose, general principles and obligations, key concepts
- The UN CRPD Committee: composition, role, involvement Disabled People's Organisations (DPOs) and jurisprudence
- State reporting and the involvement DPOs of and Civil Society (CSO)
- Your comments and questions

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - TIMELINE

- **Adoption by the United Nations General Assembly** - 13 December 2006
- **Opened for signature** - 30 March 2007
- **Entry into force** – 3 May 2008
- **First Conference of States Parties** – 31 October & 3 November 2008
- **First session of the Committee on the Rights of Persons with Disabilities** – 23-27 February 2008
- **Number of ratifications** – 162 countries worldwide, 25 EU Member States and EU itself

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - PURPOSE

Article 1 CRPD

“To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - WHAT IS UNIQUE ABOUT CRPD?

- **‘Nothing about us, without us’** - a forceful call from persons with disabilities around the world to have their human rights respected, protected and fulfilled on an equal basis with others
- A policy instrument which is cross-disability and cross-sectoral: includes all persons with disabilities, including persons with intellectual and psychosocial disabilities, and all areas of life
- Legally binding, both for public authorities and private entities

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - HUMAN RIGHTS BASED APPROACH

- The Convention marks a 'paradigm shift' in attitudes and approaches to persons with disabilities.
- Persons with disabilities are not viewed as "objects" of charity, medical treatment and social protection
- Rather as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society
- The Convention gives universal recognition to the dignity of persons with disabilities

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - HUMAN RIGHTS BASED APPROACH

Preamble of CRPD:

'Disability is an evolving concept, and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others'

Article 1 CRPD:

'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - WHAT IS DISABILITY?

Disability results from an **interaction** between a non-inclusive society and individuals:

- Person using a wheelchair might have difficulties gaining employment not because of the wheelchair, but because there are environmental barriers such as inaccessible buses or staircases which impede access
- Person with extreme near-sightedness who does not have access to corrective lenses may not be able to perform daily tasks. This same person with prescription eyeglasses would be able to perform all tasks without problems.

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - GENERAL PRINCIPLES (Art 3)

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- Equality of opportunity
- Accessibility
- Equality between men and women
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - GENERAL PRINCIPLES (Art 3)

Non-discrimination

- Fundamental principle of international human rights law
- Includes direct and indirect discrimination
- The obligation of providing reasonable accommodation for persons with disabilities
- Reasonable accommodation: 'necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms'

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - GENERAL PRINCIPLES (Art 3)

Accessibility: Important as a means to empowerment and inclusion. Both a general principle and a stand-alone article (article 9)

Access must be ensured to:

- Justice (article 13)
- Living independently and being included in the community (article 19)
- Information and communication services (article 21)
- Education (article 24)
- Health (article 25)
- Habilitation and rehabilitation (article 26)
- Work and employment (article 27) - human resource policies and practices
- Adequate standard of living and social protection (article 28)
- Participation in political and social life (article 29)
- Participation in cultural life, recreation, leisure and sport (article 30)

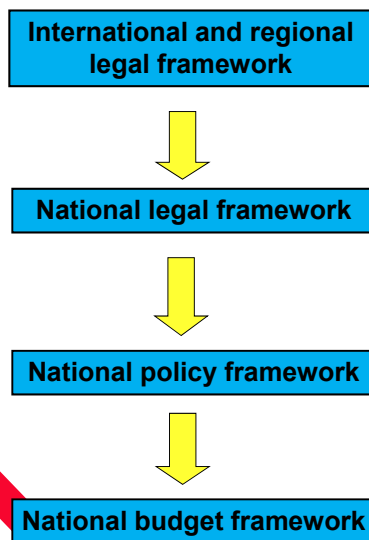
UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - GENERAL OBLIGATIONS (Art 4)

- **Law and policy review**
 - To adopt new legislation and policy to implement CRPD
 - To modify or abolish existing legislation and policy that constitutes discrimination against persons with disabilities;
 - To mainstream the human rights of persons with disabilities in all policies and programmes.
- **Research** and development of universally designed goods, services, equipment and facilities, and new technologies, including information and communications technologies, mobility aids, devices and assistive technologies
- **Training** of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - LAW AND POLICY REFORM



UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - LAW AND POLICY REFORM



Connecting laws,
policies and budgets

=

Better implementation of
laws and policies

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - RESEARCH

Research related to:

- Universally designed goods, services, equipment and facilities
- New technologies, including information and communication technologies, mobility aids, devices and assistive technologies
- Policy formulation

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - TRAINING AND AWARENESS RAISING

FOR

- Persons with disabilities
- all officials working to promote CRPD at the national, regional and local levels
- Health, legal, educational professionals (civil servants, judges, social workers, teachers, educational administrators, other educational staff, police)
- Election officials and staff (voting)
- Sign language interpreters

ON:

- Human rights model and inclusion
- Accessibility
- Reasonable accommodation,
- Legal capacity including supported decision-making
- Inclusive education

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES - RIGHTS

- Equality before the law without discrimination (article 5)
- Right to life, liberty and security of the person (articles 10 & 14)
- Equal recognition before the law and legal capacity (article 12)
- Freedom from torture (article 15)
- Freedom from exploitation, violence and abuse (article 16)
- Right to respect physical and mental integrity (article 17)
- Freedom of movement and nationality (article 18)
- Right to live in the community (article 19)
- Freedom of expression and opinion (article 21)
- Respect for privacy (article 22)
- Respect for home and the family (article 23)
- Right to education (article 24)
- Right to health (article 25)
- Right to work (article 27)
- Right to adequate standard of living (article 28)
- Right to participate in political and public life (article 29)
- Right to participation in cultural life (article 30)

THE UN CRPD COMMITTEE

- Composition
- Role
- How DPOs and persons with disabilities can be involved?
- Jurisprudence

THE UN CRPD COMMITTEE - COMPOSITION



- 18 members; 4 year mandates eligible for reelection once
- serve as independent experts
- Elected with consideration of equitable geographical distribution, representation of principal legal systems, gender balance, participation of experts with disabilities

THE UN CRPD COMMITTEE - ROLE

- Reviewing State reports and adopting Concluding Observations
- Receive individual communications and issue views on decisions (Optional Protocol)
- Undertake inquiries into States parties when there is reliable information of grave and systematic violations of the Convention (Optional Protocol)
- Hold thematic discussions (Days of General Discussion)
- Adopt General Comments (Art 12, Art 9; Art 6; Art 19; Art 24)

THE UN CRPD COMMITTEE – INVOLVEMENT DPOs

- State review  ALTERNATIVE REPORT/
BRIEF THE COMMITTEE
- Individual communications/complaints
- Inquiries  LODGE COMPLAINTS/
INITIATE INQUIRIES
- Days of General Discussion
- General Comments  PARTICIPATION/
SUBMISSIONS

STATE PARTY REPORTING

- Each State party has to submit to the Committee a report on measures taken to implement the Convention and on the progress made
 - within two years after the entry into force of the Convention
- After the initial report, the State Party must submit subsequent reports (periodic reports) at least every four years and whenever the Committee requests it.

STATE PARTY REPORTING

CRPD Committee [reporting guidelines](#):

- Conduct a comprehensive review of the measures it has taken to harmonize national law and policy with the provisions of the relevant international human rights treaties to which it is a party;
- Monitor progress made in promoting the enjoyment of the rights set forth in the treaties in the context of the promotion of human rights in general;
- Identify problems and shortcomings in its approach to the implementation of the treaties;
- Plan and develop appropriate policies to achieve these goals.

STATE PARTY REPORTING

Common core document:

- the general framework for the protection and promotion of human rights, disaggregated according to sex, age, main population groups and disability
- information on non-discrimination and equality
- effective remedies

Treaty-specific document

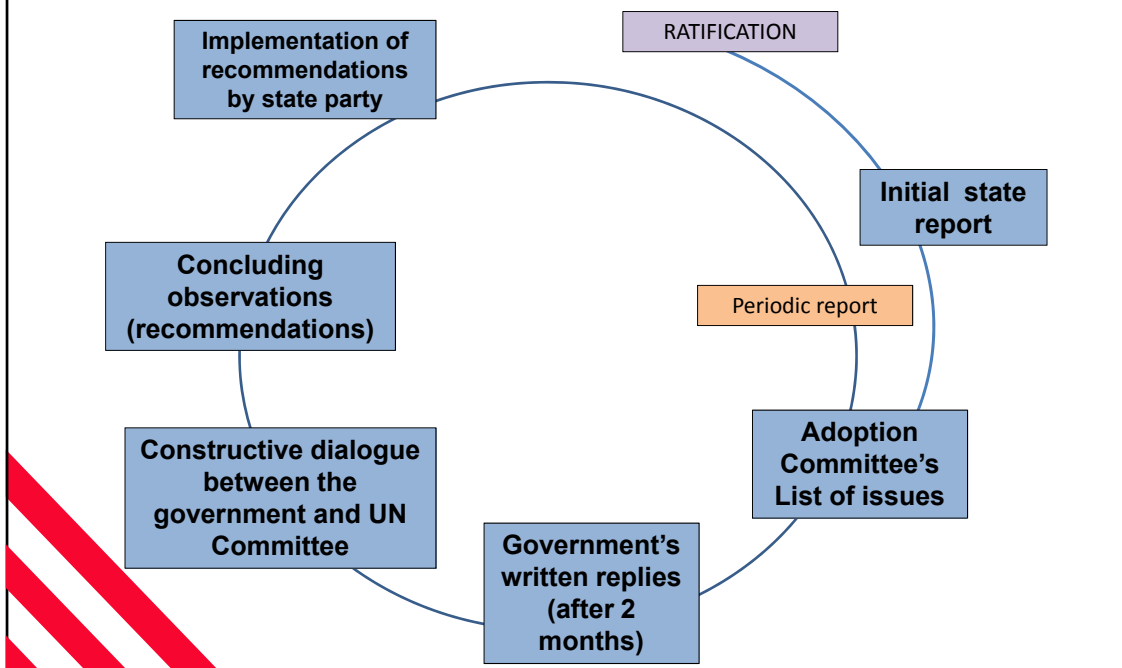
- policies, strategies and a national legal framework for the implementation of each Convention right, and available resources
- comprehensive disability anti-discrimination legislation
- monitoring mechanisms to measure progress

STATE PARTY REPORTING - STRUCTURE

Treaty-specific document (continued)

- incorporation and direct applicability of each Convention right in the domestic legal order, and relevant legal cases
- judicial and other appropriate remedies for victims' redress
- structural or other significant obstacles which impede the full realization of the Convention rights
- statistical data on the realization of each Convention right, disaggregated by sex, age, type of disability (physical, sensory, intellectual and mental), ethnic origin, urban/rural population and other relevant categories

REPORTING CYCLE IN BRIEF



STATE PARTY REPORTING

- The **list of issues** is a document of the Committee with questions and requests for more information from the state party
- The **list of issues** is written on the basis of the state report, but also takes into account information from the DPO alternative report, United Nations agencies' reports, other treaty bodies' concluding observations, etc.
- The report and the responses to the list of issues are then discussed at the next session of the Committee, during a **constructive dialogue with the state party**.
- During this constructive dialogue, the Committee asks more questions and the state party gives additional information

STATE PARTY REPORTING

- After the constructive dialogue, the Committee adopts **its Concluding Observations** based on proposals from the Committee's member who is the country rapporteur.
- The **Concluding Observations** point out the positive aspects, the factors and difficulties in the implementation of the Convention, and make concrete suggestions and recommendations for future action.
- The Concluding Observations are published and can be a powerful tool for putting leverage on the state party to take action where the Committee has identified failures or weaknesses.

INCLUSION OF DPOs IN STATE PARTY REPORTING

Article 35 (4) CRPD

When preparing reports to the Committee, States Parties are invited to consider doing so in an **open and transparent process** and to give due consideration to the provision set out in **article 4.3 of the Convention**

Para 3, Reporting Guidelines, CRPD/C/2/3

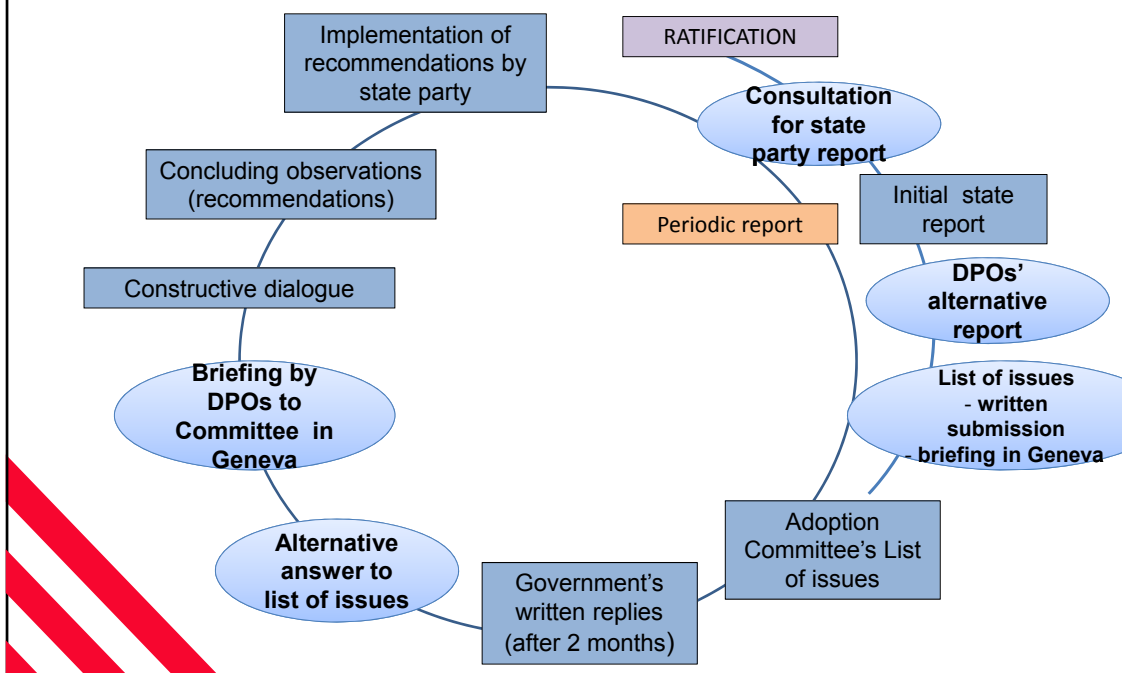
Furthermore, States Parties should encourage and facilitate the **involvement** of non-governmental organizations, including **organizations of persons with disabilities in the preparation of reports.**

Para 42, Working Methods, CRPD/C/5/4

... the Committee emphasizes the importance of the **participation and consultation of such organizations** by States parties in the preparation of their reports, in order to **reflect the reality of persons with disabilities.**

States parties are encouraged to provide **reasonable adjustments and support to enable effective contributions** from the different sectors of persons with disabilities.

REPORTING CYCLE and PARTICIPATION DPOs



REPORTING CYCLE and DPO PARTICIPATION

Step 1. The State Party should have **consultations** with civil society, including representative organizations of persons with disabilities (DPOs), to prepare its **State report**.

Step 2. State Party submits its **State report** to the Committee. DPOs submit their own **alternative reports** with **priority issues** and **concrete recommendations**.

REPORTING CYCLE and DPO PARTICIPATION

Step 3. The CRPD Committee sends the State Party a **list of issues** and questions based on concerns they have.

- DPOs can suggest issues for the **list of issues** and **questions the Committee should ask the State**, before the Committee adopts its list of issues (written submission)

- DPOs can give an **oral presentation** during the session in which the list of issues of their country will be adopted.

REPORTING CYCLE and DPO PARTICIPATION

Step 4. State Party **answers to list of issues** and questions within 2 months.

-DPOs can also give their **own responses**.

Step 5. **Constructive dialogue** between the Committee and the State Party during a plenary session.

-DPOs can give an **oral presentation** during this session

- Before the dialogue, and during the same session, DPOs could try to **meet with Committee members**, especially the **country Rapporteur**, to explain their priority issues and recommendations.

REPORTING CYCLE and DPO PARTICIPATION

Step 6. The Committee publishes its **concluding observations**, including **recommendations**

- Before the concluding observations are adopted, DPOs can identify for the Committee members the priority areas that need quick action, and suggest recommendations on the issues that were discussed during the dialogue.
- Concluding observations should be circulated widely at national level.
- Short term follow up recommendations: state party needs to provide update to the Committee within one year of adoption of the concluding observations

REPORTING CYCLE and DPO PARTICIPATION

Step 7. **Implementation and follow up plan on the Concluding observations**

- wide dissemination of the Concluding Observations, amongst the different ministries, Parliament, and other relevant bodies in the country (NHRI, Ombudsman, trade unions, education institutions, etc)
- Development of plan of action on how to implement the recommendations, allocation of budget and timeframe, responsible ministries and administrations

UPCOMING COUNTRIES FOR REVIEW

6th pre-session CRPD Committee (September 2016): adoption list of issues of Cyprus and Bosnia Herzegovina

16th session of CRPD Committee (August 2016): constructive dialogue of Italy

7th pre-session (March 2017): adoption of list of issues of Luxembourg, UK, Montenegro and Armenia (to be confirmed by the Committee)

17th session CRPD Committee (April 2017): constructive dialogue of Cyprus and Bosnia Herzegovina

INCLUSIVENESS OF THE PROCESS

- DPOs participation in the reporting cycle should **involve all persons with disabilities**, including persons with intellectual disabilities, persons with psychosocial disabilities, persons who are deaf, persons who are deafblind, persons with autism, persons under guardianship and persons living in institutions.
- State report and answer to the list of issues, as well as submissions from DPOs and CSOs should **reflect the views of** women, children, older persons, migrants (refugees, illegal migrants), indigenous and ethnic minorities and LGBTI people with disabilities, from all across the country, both in rural and urban areas.

INCLUSIVENESS OF THE PROCESS

- A coalition should be formed with the different organisations since that will strengthen your views and voice.
- To draft and defend one report all together will also be more practical. The DPO movement might be fragmented but in this process DPOs can learn from each other and come to a common understanding of the Convention.

CRPD Committee Concluding Observations

Key aspects of their jurisprudence:

- Substantive recommendations
 - Non-discrimination
 - Legal capacity
 - Forced sterilisation
 - Institutionalisation
 - Independent monitoring framework
- Procedural recommendations
 - DPO participation
 - Data collection
 - Training & awareness-raising
 - Resources

CRPD Committee Concluding Observations: Non-discrimination

- Multiple and intersectional discrimination
- Explicit recognition in the law that the denial of reasonable accommodation constitutes discrimination
- Need for remedies and penalties
- Abolition of any distinction in the period permitted by law within which a pregnancy can be terminated on the basis of disability

CRPD Committee Concluding Observations: Legal capacity

- The Committee recommends that the State party use effectively the current review process of its Civil Code and related laws
- to take immediate steps to derogate guardianship in order to move from substitute decision-making to supported decision-making, which respects the person's autonomy, will and preferences and is in full conformity with article 12 of the Convention,
- including with respect to the individual's right, on their own, to give and withdraw informed consent for medical treatment, to access justice, to vote, to marry, to work, and to choose their place of residence.
- The Committee further recommends the State party to provide training, in consultation and cooperation with persons with disabilities and their representative organizations, at the national, regional and local levels for all actors, including civil servants, judges, and social workers on the recognition of the legal capacity of persons with disabilities and on mechanisms of supported decision-making.

CRPD Committee Concluding Observations: Institutionalisation

- Repeal laws which permit for the deprivation of liberty on the grounds of disability
- until new legislation is in place, all cases of persons with disabilities who are deprived of their liberty in hospitals and specialised institutions be reviewed, and that the review include the possibility of appeal.
- adopt, in cooperation with organisations of persons with disabilities, an adequately funded strategy to deinstitutionalise persons with disabilities, including children with intellectual and/or psychosocial impairments, and ensure their social inclusion and their right to live independently in the community, with the possibility of a personal assistant or support services in the home.

CRPD Committee Concluding Observations: Forced sterilisation

repeal laws which allow for forced sterilisation and adopt legislation prohibiting the use of sterilisation of boys and girls with disabilities. And prohibit the use of sterilisation of adults with disabilities in the absence of their prior, fully informed and free consent.

Strengthen data collection

- indicators on intersectional and multiple discrimination
- gender and age sensitive indicators
- Women with disabilities
- Children with disabilities
- Minorities (Roma, African descent, indigenous persons with disabilities)
- Persons with disabilities living in rural areas
- institutionalised persons
- persons deprived of their legal capacity
- involuntary commitments to institutions
- Persons subjected to forced sterilisation
- prevalence of exploitation, and abuse and violence
- fulfilment of the employment quota in the public sector

RESOURCES

[CRPD Committee webpage](#)

[UN Convention on the Rights of Persons with disabilities](#)

[State party reporting guidelines](#)

[Guidelines for the participation of Disabled Persons Organizations \(DPOs\) and Civil Society Organizations \(CSOs\) in the work of the Committee](#) (April 2014)

[Informative note](#) of CRPD Committee secretariat on deadlines of submissions and accreditation, dates of briefing meetings, word limits, and languages for alternative submissions

REPORTING CYCLE and DPO PARTICIPATION

RESOURCES

International Disability Alliance guidance document
'[Effective Use of International Human Rights Monitoring Mechanisms to Protect the Rights of Persons with Disabilities](#)' (May 2010)

International Disability Alliance:
Compilation of Concluding Observations
([CO PDF](#) or [CO Word](#))
Compilation of List of Issues ([LoI PDF](#) or [LoI Word](#))

Webcast of the UN CRPD Committee's meetings:
<http://www.treatybodywebcast.org/category/webcast-archives/crpd/>

THANK YOU FOR YOUR ATTENTION!

QUESTIONS and COMMENTS ?

Please feel free to contact me at
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EUROPEAN DISABILITY FORUM

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Forum



European Disability Strategy (EDS) 2010-2020 & The European Accessibility Act

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The EU and the UN Convention

- 30 March 2007: the European Community **signed** the UN Convention
- 26 November 2009: Council Decision on the conclusion (**ratification**) of the Convention by the European Community
- **22 January 2011: entry into force** for the EU
- 5 June 2014: **first EU report to the UN** on the implementation of the CRPD
- All 28 EU Member States signed, 26 have ratified it



EU and UNCPRD

(mixed agreement)

Competences

Legal order & Conferral of powers

UNCPRD

1-Treaties

2-UNCPRD

3-Secondary Legislation

27 MS competences

**EU
competence**

EU competence with regard to the UNCRPD

- The rights recognised cover almost all policy fields: accessibility, employment, education, health, independent living, participation in culture and sport, civil rights
 - Mixed competences between EU and MS
 - some articles concern only Member States
 - most UNCRPD fields concern matters of shared competence
- ⇒ the EU cannot act in relation to all UNCRPD areas
- ⇒ EU and MS together can fulfil the obligations laid down by the UN Convention in a coherent manner
- ⇒ Internal implementation EU institutions, Agencies, delegations...
- ⇒ Employees
 - ⇒ Visitors



European Disability Strategy 2010-2020

Adopted on 15 November 2010

Objectives:

- To empower people with disabilities to enjoy their full rights
- To Create a barrier-free Europe for all

> It provides a strategic and multiannual framework to facilitate the implementation of the UNCRPD by the EU and support Member States in their implementation

Three main documents:

- Communication on a European Disability Strategy 2010-2020
- List of Actions 2010-2015
- Background Document with facts and figures



European Disability Strategy 2010-2020

Adopted on 15 November 2010.

- Communication on a European Disability Strategy 2010-2020
 - Accessibility of goods and services
 - Participation as equal citizens in Europe and quality community-based services
 - Equality and combating discrimination
 - Employment in the open labour market
 - Inclusive education and training
 - Social protection to combat poverty and social exclusion
 - Equal access to health services and related facilities
 - External action including EU enlargement, neighbourhood and international development programmes
- Initial plan to implement the Strategy: List of Actions 2010-2015

Reporting to the UN: art 35 CRPD

Each State Party shall submit to the Committee on the Rights of Persons with Disabilities a report:

- o on **measures taken** to give effect to its obligations under the Convention and on the **progress made**
- o **two years** after the entry into force of the Convention for that state party

Article 44 CRPD

- o Convention open to 'regional integration organizations' for signature and ratification
- o Provisions of the Convention will apply to such organizations as States Parties within the limits of their competence

Content of the Report

Focus UNCRPD entry into force for EU January 2011 to 2013 but previous information where relevant

Under each article : relevant measures, legislation, programmes, funding,...

- Introduction to EU legal framework**
- Charter of Fundamental Rights**
- Internal implementation in EU institutions**
- Addressed the declaration of competences but not limited**
- Legislation adopted, repealed, amended after the Council Decision for Conclusion**
- Case law of the Court of Justice (Dir 2000/78)**
- EU level statistics describing rights enjoyments and gaps**

Dialogue on the implementation

Article 36 consideration of the report

- List of issues –April 2015
- Response to list of issues June 2015
- Dialogue – Geneva 27-28 August 2015
- 22 MS experts as observers
- Wide range of issues
 - **EU competence MSs**
 - **Internal implementation**
- Recommendation published 7th September 2015

UNCRPD Concluding Observations EU

- *3 issues 1 year:*

Commission withdrawal from IM

Adoption EAA

Revision declaration of competences

- **Disseminate information for implementation**

DGs

EU institutions – also internal implementation

NGOs structured dialogue

- **Working with MSs**

Disability card project

Work forum

Semester

Statistics

ESI Funds

- **Reporting on the EDS progress.**



ACCESSIBILITY

EC European Disability Strategy 2010-2020

*"The Commission proposes to **use legislative and other instruments as standardisation**, to optimise the **accessibility** of the built environment, transport and ICT [...]. Based on smarter regulations principles, **it will explore the merits of adopting regulatory measures** to ensure accessibility of products and services, including measures to step up the use of **public procurement**[...]. Following further consultations with Member States and stakeholders, the Commission will consider whether to **propose a European Accessibility Act.**"*

Accessibility in the UN CRPD

- *Accessibility is a general principle of the UN CRPD (Art. 3)*
- *Article 9 Accessibility*

*State parties to undertake appropriate measures **to ensure equal access** for persons with disabilities to:*

- **the physical environment**
- **transportation**
- **information and communications, including information and communications technologies and systems & internet**
- **other facilities and services open or provided to the public, both in urban and in rural areas**

Why an European Accessibility Act?

Economic reasons

- Free circulation of accessible products & services ⇒ more accessible and cheaper products/services for 80M of EU citizens
- Divergence of national legislations ⇒ fragmentation of the EU Market ⇒ counterproductive for enterprises
- Opening markets for being ready for global competitiveness

Why an European Accessibility Act?

Legal obligations

- The UN Convention on the Rights of Persons with Disabilities (UNCRPD) entered into force for the EU in 2011
- Its obligations increase the risk of divergent accessibility legislations in MS
- The EAA helps to implement the obligations of article 9 on Accessibility

Impact Assessment

- Approved in 2013
- In-depth analysis of the accessibility legislation in nine EU Member States - covering about 80% of the EU GDP and 77% of the EU population
- 5 options discarded as not effective or realistic
- 4 options retained – assessment of detailed impacts



Retained Options

- Option 1: No further action at EU level (baseline scenario).
- Option 2: EU Recommendation defining common accessibility requirements for the selected products and services, as well as in the area of public procurement
- Option 3: EU Directive defining common accessibility requirements for the selected products and services as well as in the area of public procurement - applicable to the Member States when they regulate on accessibility.
- Option 4: EU Directive defining common accessibility requirements for the selected products and services, as well as in the area of public procurement – immediately applicable to all Member States.

Assessment of Impacts

Socio-economic

Costs for businesses due to divergence:

- Option 1: EUR 20 billion in 2020
- Option 2: cost savings of 20 %
- Option 3: cost savings of 50 %
- Option 4: cost reduction of 45 %

Efficiency and effectiveness

Consumers

SMEs and micro enterprises

What is covered under the EAA?

- Accessibility requirements for carefully selected products and services
- Same accessibility requirements to be used in other EU law (for example Public Procurement)

Products & services in the scope of the EAA

- Computers and operating systems
- ATMs, ticketing and check-in machines
- Telephones and smartphones
- TV equipment related to digital television services
- Telephony services and related equipment
- Audio-visual media services (AVMS) and related equipment
- Air, bus, rail and waterborne passenger transport services
- Banking services
- E-books
- E-commerce

How does the EAA interact with other EU law?

- **Same accessibility requirements as in existing EU law:**
 - Public procurement
 - Structural and investments funds
 - Tenders for public passenger transport services
 - Transport infrastructure

What does the **European Accessibility Act** propose?

- **Functional accessibility requirements**
- **Free movement of products and services** meeting the accessibility requirements
- **Self-declaration of conformity** (lightest option)
- **Market surveillance**
- **Defines accessibility** under already existing obligations in other EU law

What the EAA does NOT do?

- **does not prescribe** to the level of technical details how to render a product or service accessible.
- **does not set obligations** for **all** manufacturers and service providers
- **does not impose burdensome requirements**
- **does not amend** existing EU sectorial legislation on accessibility

Structure of the EAA

	Demand side	Supply side
Obligations on:	Public authorities	Private sector
Material scope:	Purchases via public procurement and public funding (ESIF, TEN-T)	Certain Products and services
Obligations:		Free circulation of products and services
	Functional Accessibility Requirements	
Possibility:	Use standards	Standards presumption of Conformity
Safeguards:	Disproportionate Burden	Disproportionate Burden and Fundamental Alteration
Other Key elements:		Self-Declaration of Compliance Market surveillance Committee
Enforcement:	PP Directives and other legal Acts	Action under National Courts
Penalties:	PP Directives and other legal Acts	Member States

What is the timeline for implementation?

- Transposition period -> Two years after entry into force
- Enter into application -> Six years after entry into force
- Implementation report -> Five years after application



Useful weblinks

European Disability Strategy 2010-2020: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:EN:PDF>

Initial plan to implement the Strategy: List of Actions 2010-2015: <http://eurlex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52010SC1324:EN:NOT>

United Nations Convention on the Rights of Persons with Disabilities: <http://www.un.org/disabilities/>

Point(s) de contact, dispositifs de coordination et mécanisme(s) indépendant(s)

Dr Gauthier de Beco

Lecturer in Disability Law

School of Law

Faculty of Education, Social Sciences and Law

University of Leeds

Introduction

Contexte : de l'élaboration de normes à la
mise en œuvre

"The struggle for human rights will be won
or lost at the national level" (Jack
Donnelly)

Introduction

Sommaire

- ❑ Article 33, paragraphe 1, de la CDPH :
point(s) de contact et dispositif de
coordination
- ❑ Article 33, paragraphe 2, de la CDPH :
mécanisme(s) indépendant(s)

Point(s) de contact

Article 33, paragraphe 1, de la CDPH

Les États Parties désignent, conformément à leur système de gouvernement, un ou plusieurs points de contact pour les questions relatives à l'application de la présente Convention.

- ❑ Obligation
- ❑ Un ou plusieurs points de contact
- ❑ Nouveauté dans un traité sur les droits de l'homme

Point(s) de contact

Fonctions

- ❑ Présentation de rapports à l'État
- ❑ Mesures de mise en œuvre de la CDPH
- ❑ Politiques sur les droits des personnes handicapées
- ❑ Participation de la société civile
- ❑ Interlocuteur (national et international)

Options

- ❑ Ministère des affaires sociales
- ❑ Points de contact supplémentaires : Espagne, Portugal, Slovaquie
- ❑ Points de contact subordonnés : Royaume-Uni, Allemagne, Autriche, Belgique

Dispositif de coordination

Article 33, paragraphe 1, de la CDPH

[Les États Parties] envisagent dûment de créer ou désigner, au sein de leur administration, un dispositif de coordination chargé de faciliter les actions liées à [l'application de la présente Convention] dans différents secteurs et à différents niveaux.

- ❑ Pas d'obligation
- ❑ Nouveauté dans un traité sur les droits de l'homme
- ❑ Coopération verticale et horizontale

Dispositif de coordination

Fonctions

- ❑ Plate-forme pour tous les services ministériels
- ❑ Différents niveaux de pouvoir dans les États fédéraux
- ❑ Pas nécessairement une instance décisionnelle
- ❑ Conseils au(x) point(s) de contact

- ❑ Facilitation d'une « gouvernance conjointe » dans les politiques relatives au handicap

Dispositif de coordination

Options

- ❑ Point de contact = dispositif de coordination (p. ex. Autriche, Belgique, Italie, Lituanie, Royaume-Uni)
- ❑ Points de contact + autres ministères = dispositif de coordination (p. ex. République tchèque, Pologne, Suède)
- ❑ Dispositif de coordination distinct (p. ex. France, Allemagne, Estonie, Espagne)
- ❑ Pas de dispositif de coordination (p. ex. Slovénie)

Mécanisme(s) indépendant(s)

Article 33, paragraphe 2, de la CDPH

Les États parties (...) désignent ou créent (...) un dispositif, y compris un ou plusieurs mécanismes indépendants, selon qu'il conviendra, de promotion, de protection et de suivi de l'application de la présente Convention. En désignant ou en créant un tel mécanisme, ils tiennent compte des [Principes de Paris].

- ❑ Désignation ou création
- ❑ Un ou plusieurs mécanismes indépendants
- ❑ Protocole facultatif à la Convention contre la torture et autres peines ou traitements cruels, inhumains ou dégradants

Mécanisme(s) indépendant(s)

Fonctions

- ❑ Promotion : sensibilisation, formation, éducation, recherche
- ❑ Protection : traitement des plaintes, *amicus curiae* (niveau national et international), assistance, représentation
- ❑ Suivi : évaluation, avis, collecte de données, renseignements généraux, observation

Mécanisme(s) indépendant(s)

Principes de 1993 concernant le statut des institutions nationales (Principes de Paris)

Reconnaissance internationale

- ❑ Déclaration et programme d'action de Vienne
- ❑ Organes des traités des Nations unies

Mécanisme(s) indépendant(s)

Principes de Paris

- ❑ Indépendance : création par la loi, implication du gouvernement et crédits suffisants
- ❑ Pluralisme : représentation (ou désignation) et coopération avec la société civile, y compris les ONG, les syndicats, les organisations socio-professionnelles intéressées et les universitaires et experts qualifiés, ainsi qu'avec les administrations à titre consultatif

Application aux mécanismes indépendants :
questions d'interprétation

Mécanisme(s) indépendant(s)

Comité de la CDPH

- ❑ « désigner un mécanisme national de contrôle indépendant, qui soit pleinement conforme aux Principes de Paris » (Argentine, 2012)
- ❑ « recommande à l'État partie de permettre aux acteurs de la société civile, notamment aux organisations qui représentent les personnes handicapées, de participer pleinement et de façon régulière à la surveillance de l'application de la Convention » (Danemark, 2014)
- ❑ « recommande aux Länder de se doter de leurs propres mécanismes de surveillance indépendants de manière à coordonner davantage les politiques et pratiques en matière de handicap menées dans le pays » (Autriche, 2013)

Mécanisme(s) indépendant(s)

Cadre

- ❑ Option 1 : institution nationale des droits de l'homme et/ou instance chargée du respect de l'égalité
P. ex. Allemagne, Royaume-Uni (4), France (2), Belgique
 - ❑ Option 2 : institution de médiation
P. ex. Lettonie, Espagne, Chypre, France, Lituanie, Pologne
 - ❑ Option 3 : autre instance
P. ex. Autriche, Slovaquie, Espagne
- Pas de modèle standard : multiples combinaisons possibles !

Niveau national

Danemark

- ❑ Article 33, paragraphe 1, de la CDPH : ministère des affaires sociales + comité interministériel de fonctionnaires sur les questions liées au handicap
- ❑ Article 33, paragraphe 2, de la CDPH : Institut danois des droits de l'homme + Conseil danois sur le handicap + Médiateur parlementaire

Slovénie

- ❑ Article 33, paragraphe 1, de la CDPH : ministère du travail, de la famille et des affaires sociales
- ❑ Article 33, paragraphe 2, de la CDPH : Conseil slovène des personnes handicapées

Conclusion

Le système de suivi le plus complet jamais créé pour un traité international sur les droits de l'homme

Pas un but ultime, mais un processus permanent d'apprentissage par la pratique

Ressources

Livres

- de Beco, G. et Murray, R., *Commentary on the Paris Principles on National Human Rights Institutions* [Commentaire sur les Principes de Paris concernant les institutions nationales sur les droits de l'homme] (Cambridge : Cambridge University Press, 2014).
- de Beco, G. (éd.), *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention* [Article 33 de la Convention des Nations unies relative aux droits des personnes handicapées : structures nationales d'application et de suivi de la Convention] (Leiden/Boston : Martinus Nijhoff Publishers, 2013).

Autres

- de Beco, G., *Study on the Implementation of Article 33 of the UN Convention on the Rights of Persons with Disabilities in Europe* [Étude sur l'application de l'article 33 de la Convention des Nations unies relative aux droits des personnes handicapées en Europe], étude commandée par le Bureau régional pour l'Europe du Haut Commissariat aux droits de l'homme des Nations unies (HCDH), juillet 2011. http://europe.ohchr.org/Documents/Publications/Art_33_CRPD_study.pdf.
- de Beco, G., 'Article 33 (2) of the UN Convention on the Rights of Persons with Disabilities. Another Role for National Human Rights Institutions?' [Article 33, paragraphe 2, de la Convention des Nations unies relative aux droits des personnes handicapées. Un nouveau rôle pour les institutions nationales des droits de l'homme ?], (2011) 29 (1) *Netherlands Quarterly of Human Rights* 84-106.

Conclusion

Merci pour votre attention !

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g.debeco@leeds.ac.uk



Application de la CDPH des NU : phase de suivi
Article 33, paragraphe 3, de la CDPH : associer les
organisations de personnes handicapées et la société civile

An-Sofie Leenknecht, Chargée des droits de l'homme, FEPH,
Académie de droit européen, Trèves, 23 mai 2016

SOMMAIRE

- L'association des organisations représentant les personnes handicapées (ORPH) dans l'application de la CDPH (art. 4, par. 3, et art. 33, par. 1, de la CDPH)
- L'association des ORPH dans le suivi de la CDPH (art. 33, par. 3, de la CDPH)
- Exemple d'examen de l'UE et association du FEPH et des membres devant le Comité de la CDPH

PRINCIPES GÉNÉRAUX SUR LA PARTICIPATION ET L'INCLUSION

- La participation est primordiale pour cerner correctement les besoins spécifiques et accroître l'autonomie individuelle
- La Convention reconnaît la participation et l'intégration pleines et effectives à la société comme :
 - Un principe général (article 3)
 - Une obligation générale (article 4)
 - Un droit politique fondamental (articles 29 et 30)

« Rien qui nous concerne sans nous »

Convention relative aux droits des
personnes handicapées

PARTICIPATION À LA PRISE DE DÉCISION

Article 4, paragraphe 3

- Renforcement des mécanismes de consultation au sens de l'article 4, paragraphe 3
- Participation des personnes handicapées et des organisations qui les représentent, y compris les femmes et les enfants, à tous les niveaux de la prise de décision publique
- Consultation avec les ORPH sur la mise en place de services d'accompagnement permettant aux personnes handicapées de mener une vie indépendante selon leurs propres choix
- Consultation avec les ORPH sur la formation à la reconnaissance de la capacité juridique et aux mécanismes d'accompagnement à la décision
- Consultation avec les enfants handicapés et leurs parents sur l'accompagnement nécessaire pour l'exercice du droit à l'éducation
- Consultation sur la rédaction de nouveaux textes constitutifs, législatifs et politiques
- Projets de coopération internationale organisés dans le pays

PARTICIPATION À LA PRISE DE DÉCISION

Principe transversal de bonne gouvernance

- Les États doivent adopter un cadre juridique favorable à la participation directe et indirecte des personnes handicapées à l'élaboration des lois et des politiques
- Les lois et les politiques qui limitent la capacité de participation des personnes handicapées et de leurs organisations représentatives doivent être amendées et abrogées
- Les organisations représentatives doivent être impliquées et consultées préalablement à toutes les étapes de la prise de décision publique, y compris avant l'adoption de nouvelles lois et politiques
- La jurisprudence du Comité de la CDPH demande l'instauration de mécanismes et de protocoles formels pour la tenue de consultations systématiques à tous les niveaux de pouvoir (conseils consultatifs ou autres structures)

PARTICIPATION À LA PRISE DE DÉCISION

Article 4, paragraphe 3

Le Comité de la CDPH recommande aux États parties :

« a) de concevoir, d'adopter et d'appliquer une stratégie visant à la pleine intégration des organisations de personnes handicapées dès les prémises de toute décision politique pertinente pour les personnes handicapées, dans tous les domaines, y compris la mise en œuvre et le suivi des Objectifs de développement durable ;
(b) d'accorder un soutien financier suffisant au renforcement des capacités et à la participation autonome de ces organisations dans toutes les décisions. »

Observations finales sur la Lituanie
Avril 2016

PARTICIPATION AU SUIVI AU NIVEAU NATIONAL

- **Législation et politiques** : créer une instance de suivi indépendante dans le droit fil des Principes de Paris
- **Participation des organisations de personnes handicapées:**
 - garantir, en priorité, la pleine participation des personnes handicapées et de leurs organisations représentatives dans le processus de suivi
 - instituer un mécanisme de suivi indépendant pratiquant une consultation permanente avec les ORPH
- **Ressources** : allouer les ressources nécessaires au mécanisme de suivi indépendant (conformément aux Principes de Paris) pour qu'il mène à bien sa mission de suivi de l'application de la CDPH

PARTICIPATION AU SUIVI AU NIVEAU NATIONAL

Recommandations du Comité de la CDPH

« Fournir aux organisations de personnes handicapées et autres organisations de la société civile les **ressources appropriées**, qui permettent leur participation pleine et effective aux travaux nationaux d'application et de suivi »

Le Comité s'est dit préoccupé qu'une instance de suivi indépendante manque de « moyens pour atteindre les régions rurales. Il craint également que les organisations de personnes handicapées et autres organisations de la société civile **reçoivent un soutien insuffisant** du gouvernement, qui ne leur permet pas de participer à l'application et au suivi à l'échelle nationale. »

Observations finales adressées à l'Allemagne en 2015

PARTICIPATION AU SUIVI AU NIVEAU NATIONAL

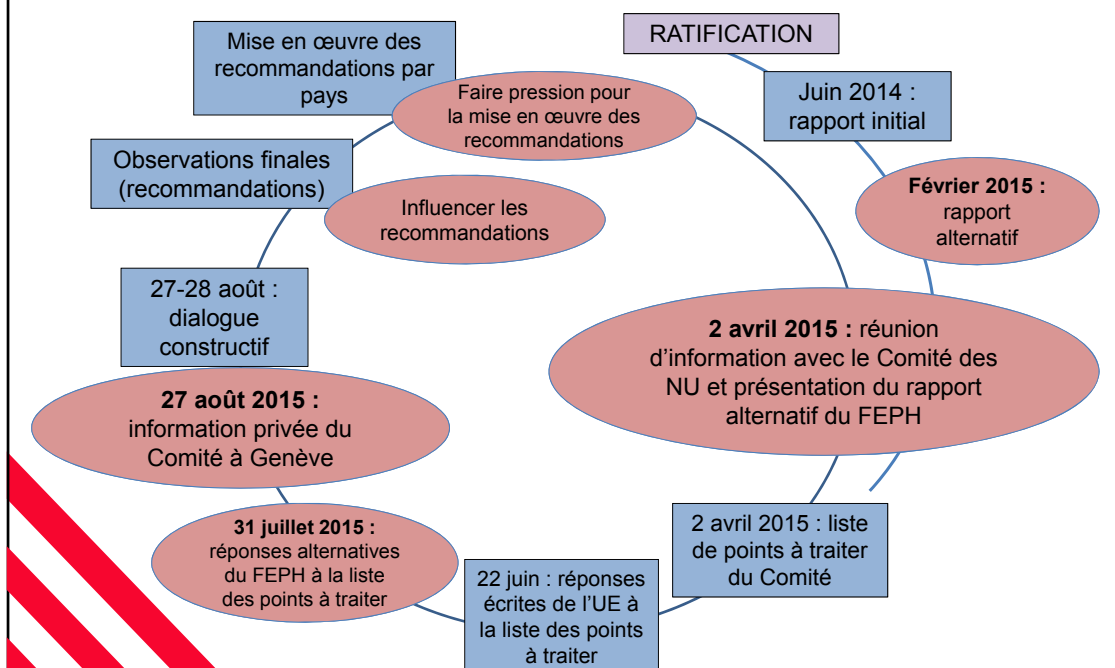
- La plupart des instances de suivi sont ouvertes aux ORPH dans l'Union
- Exemples :
 - En Italie et en Slovénie, l'instance de suivi est composée à un tiers de représentants d'ORPH
 - En Slovaquie, la moitié des membres de l'instance de suivi représentent des ORPH
 - Au Conseil lituanien sur le handicap, l'une des deux branches de l'instance de suivi nationale, la moitié des membres sont issus d'ORPH
 - Au Danemark, les ORPH sont représentées au conseil d'administration de l'Institut danois des droits de l'homme, ainsi qu'au Conseil des droits de l'homme, qui supervise les travaux de l'Institut
 - L'Espagne est un cas unique, une ORPH constituant elle-même l'instance de suivi
 - Au niveau de l'UE, le FEPH fait partie du cadre de suivi (aux côtés de l'Agence des droits fondamentaux, du Médiateur européen et du Parlement européen)

PARTICIPATION AU SUIVI INTERNATIONAL

Exemple du Forum européen des personnes handicapées et de ses membres

- L'UE a soumis son premier rapport d'État aux Nations unies en juin 2014
- Le Comité de la CDPH des Nations unies a examiné l'UE en avril et août 2015
- Le FEPH et ses membres ont rédigé un rapport alternatif, des propositions de listes de points à traiter et des réponses alternatives à la liste de points à traiter
- Présence du FEPH à Genève - 3 événements parallèles en avril et août 2015 pour informer le Comité sur les priorités du FEPH
- Observations finales adoptées en septembre 2015
- Feuille de route claire pour la mise en œuvre de la CDPH au cours des 4 prochaines années et fondement pour les activités de pression du FEPH et des membres au niveau national et de l'UE

Opportunités pour les ORPH : rôle du FEPH dans le processus d'examen de l'UE



OBSERVATIONS FINALES DU COMITÉ DE LA CDPH À L'UE

Article 4, paragraphe 3, de la CDPH

- Le Comité s'inquiète de l'absence de structure transversale encadrant la consultation parmi les différentes instances de l'Union européenne et les personnes handicapées, y compris les femmes et les enfants en situation de handicap, par le biais de leurs organisations représentatives.
- Mettre en place un dialogue structuré avec les personnes handicapées et leurs organisations représentatives dans tous les processus décisionnels de l'UE, avec un budget indépendant et un financement suffisant pour la consultation et la participation des personnes handicapées.



La délégation du mouvement européen des personnes handicapées à Genève

RESSOURCES

[Rapport de la Rapporteuse spéciale des Nations unies sur les droits des personnes handicapées concernant la participation à la prise de décision](#)

[Rapport alternatif du FEPH](#)

[Rapport de l'Union européenne et Liste des points à traiter du Comité des Nations unies](#)

[Observations finales du Comité de la CDPH adressées à l'Union européenne](#)

Répertoire comprenant les documents de position du FEPH sur www.edf-feph.org

MERCI POUR VOTRE ATTENTION !

UNE QUESTION ou UN COMMENTAIRE ?

N'hésitez pas à me contacter à l'adresse
Ansofie.Leenknecht@edf-feph.org



EUROPEAN DISABILITY FORUM

.....
An-Sofie Leenknecht, European Disability
Forum

IMPLEMENTING THE UNCRPD THE LEGISLATIVE PHASE



AN OBLIGATION TO UNDERTAKE A COMPREHENSIVE LEGAL REVIEW

Article 4.

“States Parties undertake to adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention.”

“States parties undertake to take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities.”



THE NATURE OF THE CHALLENGE



It would be deceiving the peoples of the world to let them think that a legal provision was all that was required to implement certain promises, when in fact an entire social construct had to be transformed.

René Cassin

A central image of a glass of water, with two white curved arrows pointing towards it from the left and right sides.

PARADIGM

The way we see the problem is the problem



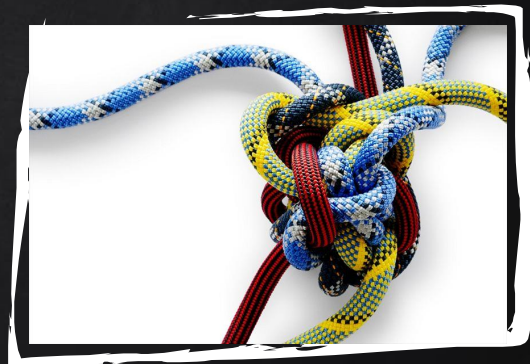
WHAT HAPPENS WHEN A PARADIGM SHIFTS

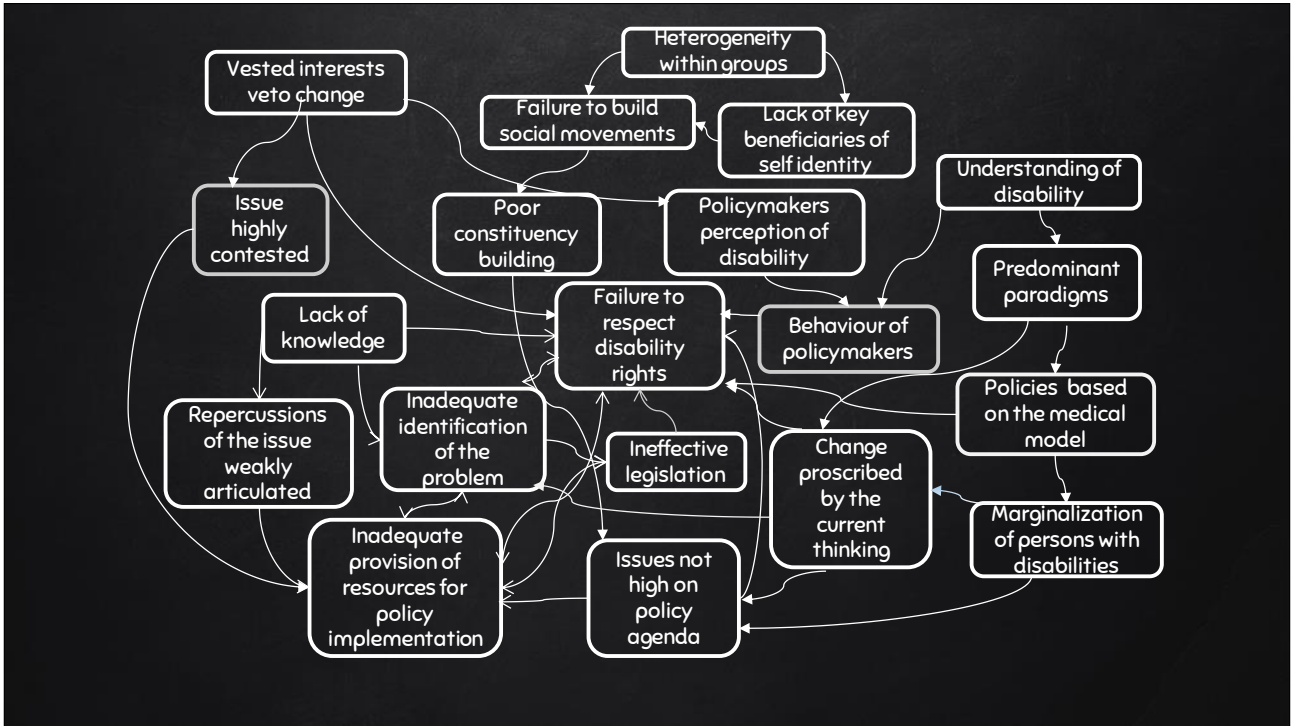


All changes meet resistance
If there is no resistance, there
is no change....



Disability policies are deeply embedded socially and culturally. Change involves coordinated action in various domains by a range of stakeholders, including organisations (government agencies at all levels), non profit organisations, private businesses and individuals.





2.

THE UNCRPD APPROACH TO DISABILITY



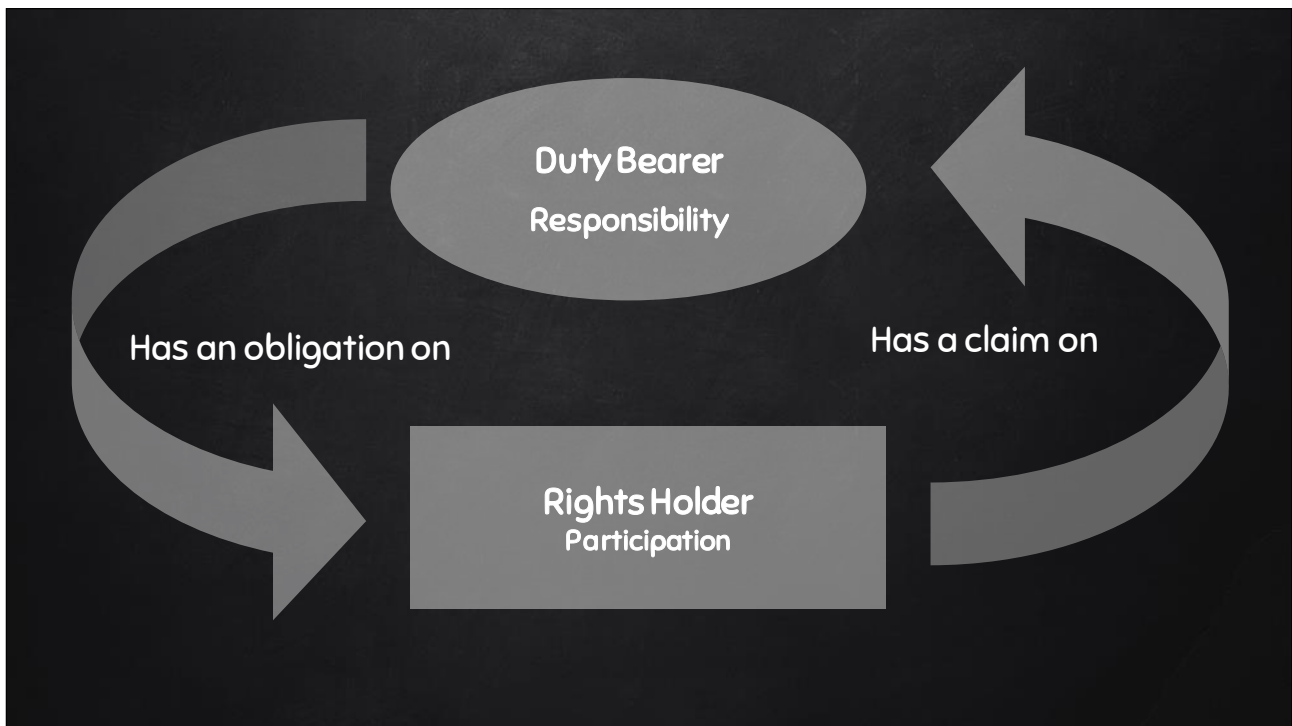
NEEDS VS RIGHTS

Needs

- X are to be assessed
- X do not always implies duties
- X can be met with charity or benevolence
- X are often associated with non legal requirements
- X what is required, specific
- X can be ranked in a hierachy

Rights

- X are to be realized
- X always implies correlative duties
- X are always mandatory
- X are always associated with legal requirements
- X what is inherent to every human being
- X cannot be ranked in a hierarchy



Empowering people
with disabilities to
exert their rights

Strengthening the
accountability of duty
bearers

Changes in

- Policies
- Practices
- Institutions
- Attitudes
- Behaviors

3.

DESIGNING EFFECTIVE LEGISLATION
FOR IMPLEMENTING THE UNCRPD



A "GOOD" LAW



Has to be consistent
with the guiding
principles of the UNCRPD

Has to be effective in
delivering the intended
outcomes of the UNCRPD
for persons with disabilities



Laws are like sausages. It is
best not to see them being
made...

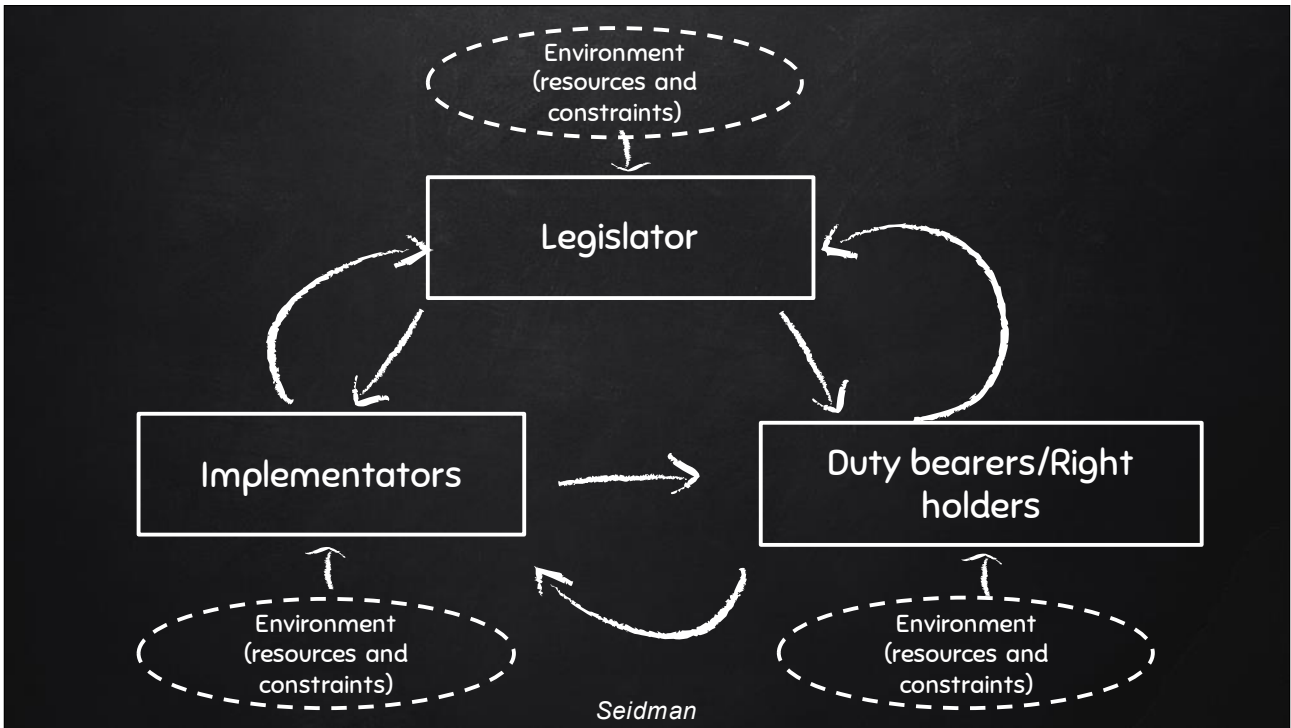
Otto von Bismarck



DRAFTING
LEGISLATION
FOR SOCIAL
CHANGE

Why do people behave as they do in the face of a rule of law ?



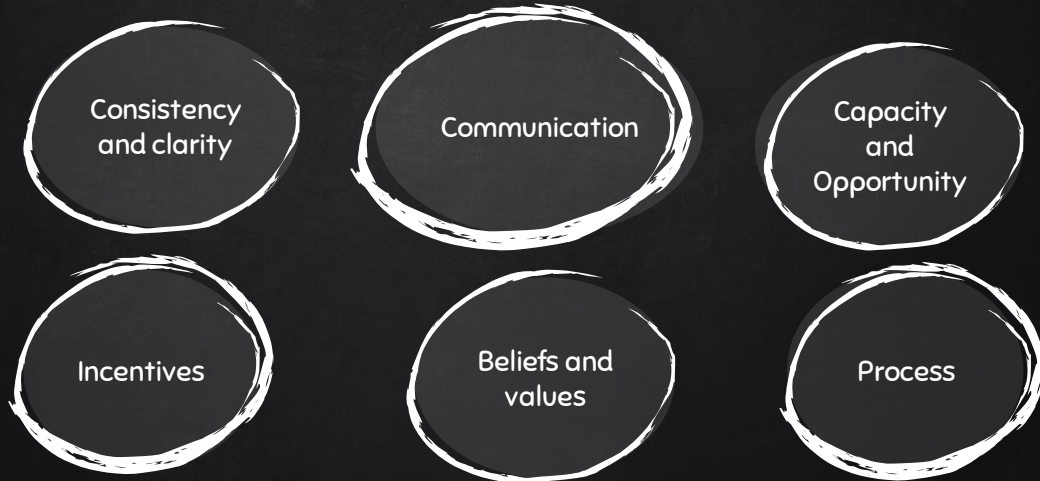


A cut and paste approach for drafting legislation doesn't not work





MAIN FACTORS AFFECTING COMPLIANCE



ISSUES RELATED TO THE RULE ITSELF

Identification of the problem

The provision does not address the causes of the problem at issue.

Clarity and Unambiguousness

The provision doesn't allow to specify sufficiently the required behaviours.

Accountability of the implementators

The provision allows implementing institutions to behave in non transparent and non participative ways.

WHAT IS THE
PROBLEM ?



Without knowing what a
law commands, no one
can consciously obey it





Do the relevant actors have the knowledge, skills, and resources to behave as the law prescribes ?



Does the rule provide enough incentives – including threat of sanction – for encouraging obedience ?





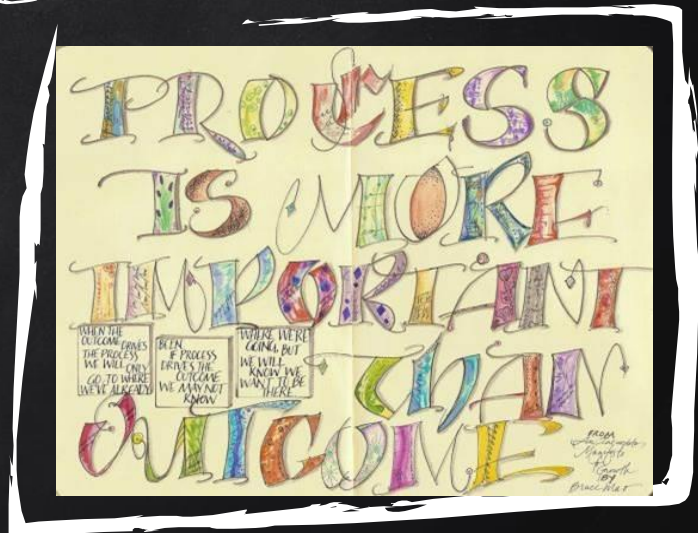
Does the requested behavior fit with the core beliefs and values of the actors?



THE IMPACT OF
THE SOCIAL
NORMS

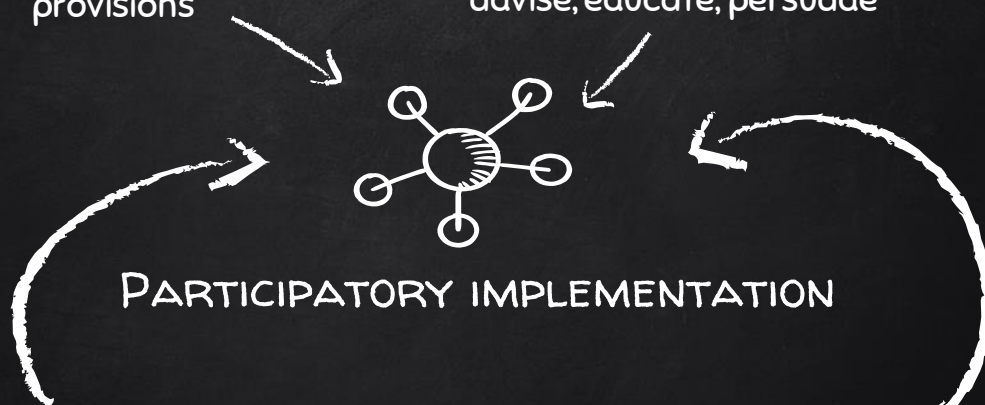


Participatory processes are a key factor for promoting social change



Direction setting legal provisions

External independent body to inform, advise, educate, persuade



PARTICIPATORY IMPLEMENTATION

Incentives to encourage organisational scrutiny and action to promote equality

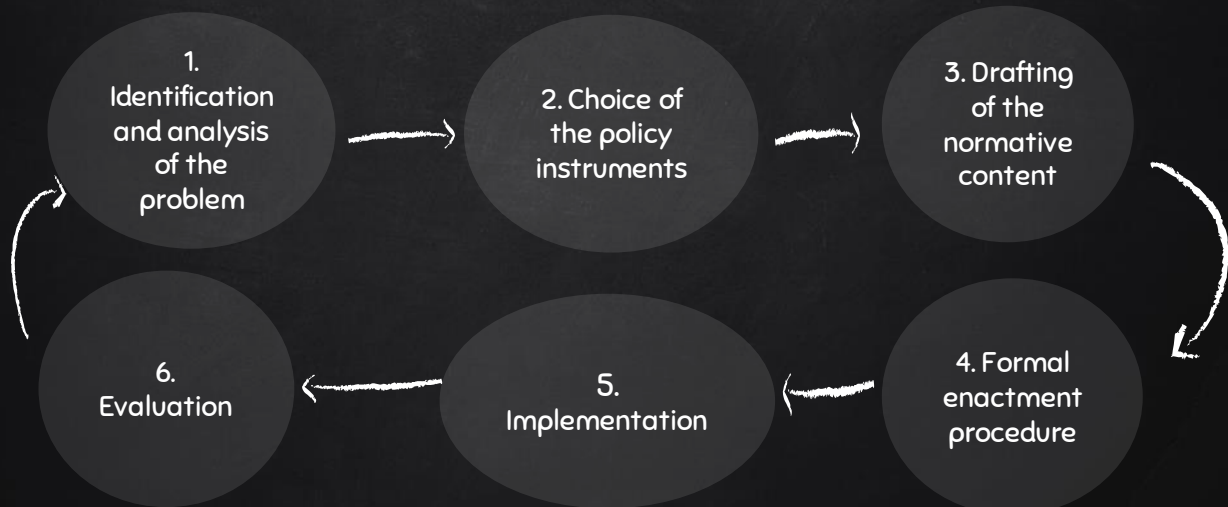
Mechanisms for effective deliberation/participatory decision making

4.

LEGISLATIVE PROCESSES FOR THE QUALITY OF THE IMPLEMENTATION OF THE UNCRPD



THE LEGISLATIVE PROCESS AS A LEARNING LOOP



“EU Disability law and the UN Convention on the Rights of Persons with Disabilities”

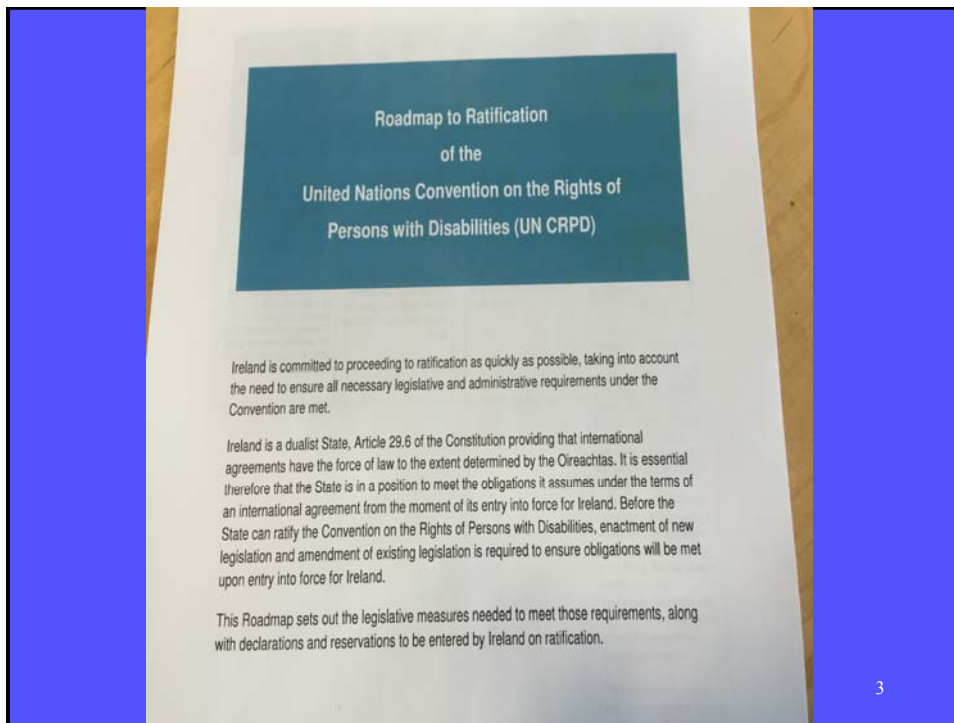
**Legislating for ratification; disability impact
assessments; and consultation mechanisms
in Ireland**

**Deaglán Ó Briain
Department of Justice and Equality**

Trier, 23 May 2016

Content of presentation

- Legislating for CRPD
- Disability impact assessments – formal procedures
- Consultation mechanisms and processes; including
- New Disability Inclusion Strategy



Ireland's approach to legislating for CRPD

- 'Progressive realisation' applies to services and quality of services, but not to law
- Ireland is a dualist state – international conventions not normally incorporated directly in domestic law
- Ratification is final step of bringing our domestic legislation up to the required standard, not a first step
- Consultation is central to how we address social issues

Ireland's approach to legislating for CRPD, *continued*

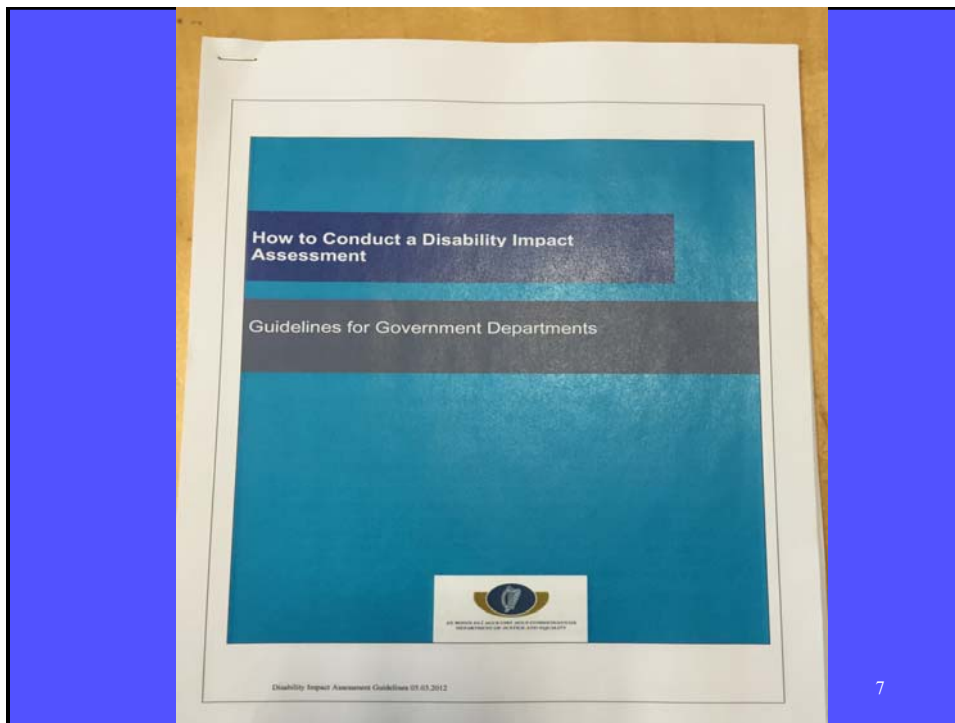
- How do we know what we are ratifying?
- National Disability Authority – legal analysis
- Vienna Convention on the Law of Treaties – Article 31
- CRPD – articles 36 and 39, role of Committee of Experts
- General Opinions, and Declarations

5

Ireland's approach to legislating for CRPD, *continued*

- Roadmap to ratification, published October 2015
- Assisted Decision-Making (Capacity) Act 2015
- Miscellaneous Provisions Bill – for enactment by end-2016. Key issues:
 - Mechanisms, including PwD participation;
 - Reasonable accommodation – ‘nominal’ v ‘disproportionate’ cost;
 - Deprivation of liberty ; and
 - Archaic language and prohibitions.

6



7

Disability impact assessments in Ireland

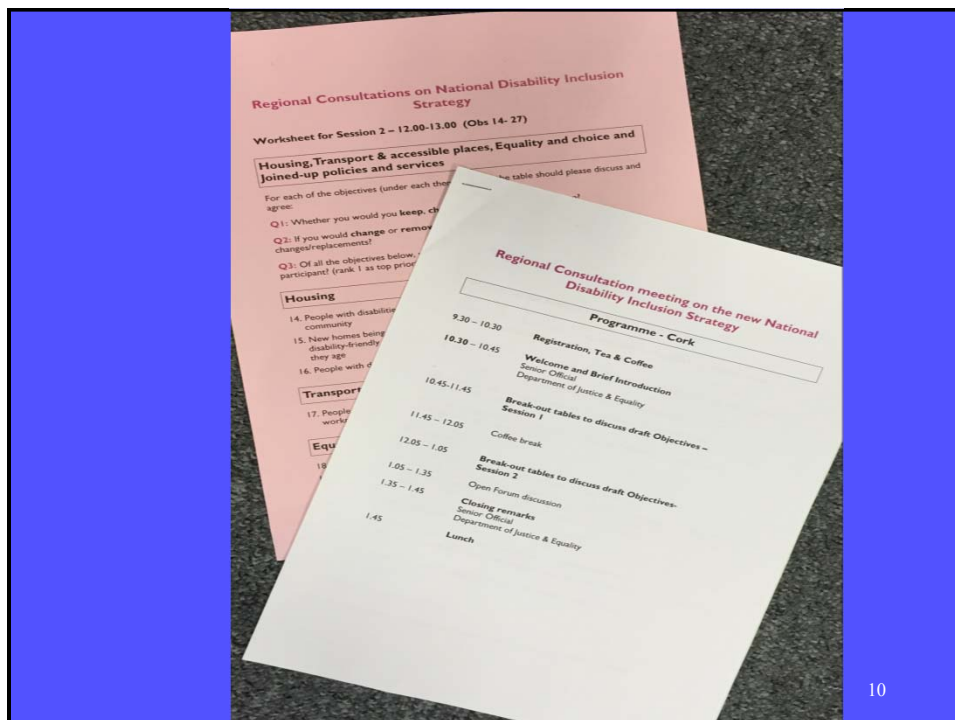
- Guidelines published March 2012, contain methodology, policy rationale and examples
- Templates, additional resources and context
- Requirement for all substantive proposals submitted to Government
- Other relevant assessment obligations – gender, poverty and rural
- Evidence of positive impact?

8

Consultation mechanisms and processes

- Disability Act 2005 – sectoral plans
- Departmental Consultative Committees
- National Disability Strategy:
 - Policy and operational framework
 - Disability Stakeholders Group (DSG)
 - Strategy Steering Group
- New Disability Inclusion Strategy 2016 – 2020

9



10

Consultation mechanisms and processes, *continued*

- Disability Inclusion Strategy 2016 – 2020
- 3 Phase consultation process:
 - Phase 1 – themes
 - Phase 2 – high-level objectives
 - Phase 3 – detailed commitments for action
 - DSG, regional public meetings, online survey, submissions, analysis by National Disability Authority
- Programme for new Government – Cabinet level State Secretary

11

Conclusion

- Disability impact assessment processes need to be targeted
- No substitute for participation in consultative forums that work well and have a formal status
- Resource and time implications for both sides
- Strong and civil society voice

12

**Legal capacity: meeting
the challenge of support -
between independence
and protection**

Camille Latimier

Trier, 23 May 2016

Introduction

Decision-making

- Rational decisions?
- External influences: culture, preferences, social relationships
- Need for expert advice
- Decisions might not be in our "best interests"
- The right to make mistakes, to make bad decisions

Decision spheres



Health

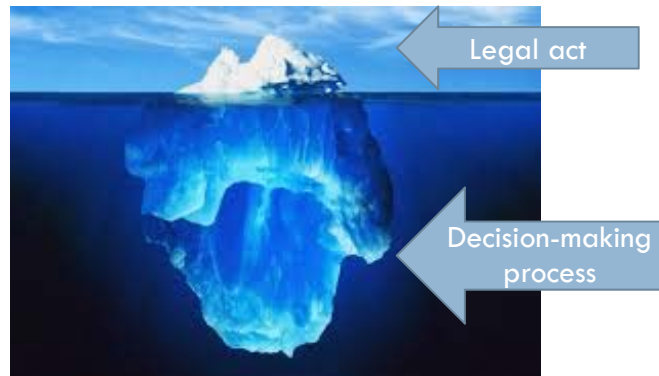


Money, property



Personal life - where and whom to live with, what support, work, private life, family

Decision-making



What obstacles do disabled people face?

- Legal incapacity, guardianship, trusteeship and other substitute decision-making measures
 - Around half of the people with an intellectual disability questioned had been either entirely or partially deprived of their legal capacity and placed under different forms of guardianship
 - Guardians generally take charge of financial matters, but it was the case that they also controlled other aspects of the lives of those concerned
 - Guardians also decide where the person lives (with or without their consent): this can cause a deprivation of freedom

Choice and control: the right to independent living, experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States, Fundamental Rights Agency, 2012

What obstacles do disabled people face?

- Access to justice
 - ▣ People under guardianships have difficulty in asserting their rights
 - ▣ Lack of support: carers or family members are generally less willing to assist in lodging an official complaint
 - ▣ Fear of retribution
 - ▣ Lack of knowledge: how and with whom to lodge a complaint

Article 12 of the Convention on the Rights of Persons with Disabilities

Recognition before the law - Article 12

1. Persons with disabilities have the right to recognition everywhere as persons before the law.
2. Persons with disabilities enjoy **legal capacity** on an equal basis with others in all aspects of life.
3. They have access to appropriate support, which they **may** require in order to exercise their legal capacity.
4. They must have appropriate and effective safeguards to prevent abuse.

Article 12 - continued

Para. 4 Safeguards against abuse:

- ▣ Respect the **rights, will and preferences of the person concerned**
- ▣ Free of conflict of interest and undue influence
- ▣ Measures are proportional and tailored to the person's circumstances
- ▣ For the shortest time possible
- ▣ Subject to regular, independent and impartial review.

Article 12 - continued

Para. 5 Persons with disabilities have the right to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit

The consequences of Article 12

- Recognition of the universal legal capacity for all people with no discrimination based on disability
- The Convention does not authorise guardianships or trusteeships or any other form of substitute decision-making or automatic loss of rights
- New forms of support (formal and informal) and safeguards are required
- **The recognition of legal personality is a prerequisite for exercising the other rights contained in the Convention.**

General Comment No. 1

Insights provided by the Committee

Background

- Analysis of the obligations resulting from Article 12
- "Existence of a general misunderstanding regarding the exact scope of the obligations" resulting from Article 12
- Human rights-based model of disability

Hence General Comment No. 1 on Article 12

Legal capacity versus mental capacity

- Legal capacity is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency).
 - ▣ Make legally-binding provisions with others: personal affairs, healthcare, property, finances, financial credit (see Article 12(5))
- To be differentiated from mental capacity:
 - ▣ the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors (social, environmental).

Support

- “Support” is a broad term that encompasses **both informal and formal support arrangements**, of varying types and intensity. (para. 17)
- **The type and intensity of support** to be provided will **vary significantly** from one person to another owing to the diversity of persons with disabilities. (para. 18)
- Some people may not wish to exercise their right to support (para. 19)

RPD Committee, General Comment No. 1 on Article 12

Forms of support

- *One or several trusted persons;*
- *Peer support;*
- *Defending their interests (including self-representation);*
- *Assistance with communication;*
- *Non-conventional methods of communication;*
- *Planning methods;*
- *Measures relating to universal design and accessibility (information which is easy-to-read and understand).*

Will and preferences

- The principle of "best interests" is not a safeguard pursuant to Article 12 regarding adults.
- **The "will and preferences" paradigm** must replace the "best interests" paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others.

*RPD Committee, General Comment No. 1 on Article 12
(para. 21)*

Changing the paradigm

- The Convention is implemented progressively, **but this does not apply in the case of the provisions on non-discrimination and on legal capacity.**
- *"The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with Article 12 of the Convention."*

RPD Committee, General comment No. 1 on Article 12 (para. 28)

The challenge

Substitute decision-making regime	Supported decision-making system
Medical diagnosis	Individual assessment of the support needs
A response - an adapted model with several variations	One or several types of support which could be combined together
No distinction between the areas of support	Identifying areas where support is required, and the right tools
No proper review; formulaic assessment	Individual evaluation, planning and (re)-assessment (needs do change)
An "easy" model - a unique response	A complex model where a set of responses and support models exist

The implications

- Legal, political, financial, social:
 - Where is the boundary with support provided by social services? Implications in relation to an ageing population
 - What role is there for justice in terms of evaluating needs? Whom to work with?
 - How to deal with prejudices in society and attitudes towards persons with a disability?
 - How to keep flexibility in daily decision-making?
 - How to check that the person has been well supported?
 - Insurance for support persons and responsibility
 - The cost?

The principles

Considering supported decision-making in practice

RPD Committee, General comment No. 1 on Article 12 (para. 29)

The key principles (a)

- Supported decision-making must be **available to all**. A person's level of support needs, especially where these are high, should not be a barrier to obtaining support in decision-making;

The key principles (b)

- All forms of support in the exercise of legal capacity, including more intensive forms of support, must be based **on the will and preference of the person**, not on what is perceived as being in his or her objective best interests;

An inclusive approach

- In order to develop an inclusive approach to legal capacity, we need to reconsider "who" exercises it and "how"
- We need to think about other criteria of personhood
 - ▣ Someone who expresses an intention and "will" to others
 - ▣ Someone who has a "personal identity" over time - whose story can be told by someone

An inclusive approach

- All individuals have a will - which can be expressed by the individual... or interpreted and described by others (trusted persons)
- A person's will or intentions form the basis of competent decision-making...
 - ▣ People are not incompetent or inept - the decision-making processes are

Practice

- Everyone has full legal capacity without discrimination on the basis of disability.
- Legislation should provide for a presumption of capability. ~~Disability=incapacity~~
- Art. 5 CRPD prohibits all discrimination on the basis of disability.
- Legislation should therefore be disability-neutral and should be amended to include a **presumption of capability**.

Practice

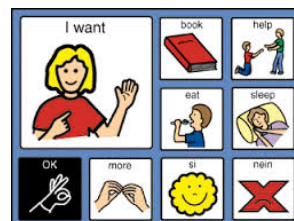
- Practice in cases of persons with a disability or multiple disabilities, without verbal communication
 - ▣ Keep a record of the person's methods and forms of communication, and habits
 - ▣ Use their personal identity and story to determine the support needs, not the medical or psychological report
 - ▣ Use witnesses who can talk about the person's trusting relationships (family, friends, etc.)

The key principles (c)

- A person's **mode of communication** must not be a barrier to obtaining support in decision-making, even where this communication is non-conventional, or understood by very few people;

The basis

- Communication and alternative communication tools are in place to ensure the inclusion of persons with severe disabilities or with complex needs.
- The communication system is key if we are to talk about supported decision-making.



Practice - British Columbia example

- The test of incapacity to enter a Representation Agreement is very low. It is based on will/feelings/trust:
 - That the adult communicates the desire to have a representative;
 - That the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others;
 - That the adult has a relationship with the representative which is characterised by trust.

The key principles (d)

- Legal recognition of the support person(s) formally chosen by a person must be available and accessible, and States have an obligation to facilitate the creation of support, particularly for **people who are isolated and may not have access to naturally occurring support in the community**. The measures taken must include a **mechanism for third parties to verify the identity of a support person as well as a mechanism for third parties to challenge the action of a support person** if they believe that the support person is not acting in accordance with the will and preferences of the person concerned;

Practice - "support circles"

- Circles Network, UK and PLAN in Canada create relationships and a social fabric for isolated people or those with few relationships.
- Support from only one person can lead to dependency, control, abuse and a unilateral perception of the will of the individual.
- A group comprising peers, friends, family members, neighbours, etc. can provide more effective and reliable support to an individual.
- Varied and long-term trusting relationships can make a difference to the lives of individuals.

The role of the support circle

A balanced circle protection



An unbalanced circle no control



Safeguards and protection against abuse

- NIDUS, British Columbia
- The role of a national agency (created by law):
 - ▣ Provide information and assistance regarding supported decision-making and reasonable arrangements
 - ▣ Maintain and update a comprehensive register of all existing support persons, facilitators and monitors
 - ▣ Listen to concerns and complaints coming from individuals, third parties, support persons, citizens who feel involved - mediation?
 - ▣ And unclog the courts?

The key principles (e)

- In order to comply with the requirement, set out in Article 12, Paragraph 3, of the Convention, for States parties to take measures to “provide access” to the support required, States parties must ensure that support is available at nominal or no cost to persons with disabilities and that lack of financial resources is not a barrier to accessing support in the exercise of legal capacity;

The key principles (f)

- Support in decision-making **must not be used as justification for limiting other fundamental rights** of persons with disabilities, especially the right to vote, the right to marry or establish a civil partnership and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty;

Support options

- Individual and flexible measures: a specific response for each person
- Supported decision-making must be arranged in a flexible way:
 - One or a group of tasks: daily financial affairs, personal affairs, health, accommodation, legal representation
 - One or several persons can be nominated as support persons with different tasks.

Finances and property

- Assets, real estate, finance and contracts:
 - A sensitive issue
 - Protection against irreversible damages (right to make an error)

- Which arrangements and support?
 - Access to bank accounts
 - Administration of property by a trusted person on behalf of the beneficiary (trust fund)



The key principles (g)

- The person must have the right to **refuse support and terminate or change the support relationship at any time;**

Self-advocacy and independence

- Promote the emancipation, empowerment and independence of disabled persons
- Work with families and professionals
- Self-advocacy from a very young age is important
- Learn to make decisions



The key principles (h)

- **Safeguards** must be set up for all processes relating to legal capacity and support in exercising legal capacity. The goal of safeguards is to ensure that the person's **will and preferences** are respected.

Which safeguards?

1. National agency/register
2. Court - competencies
3. Access to legal advice
4. Access to lawyers/representatives:
 1. advise people on their decision-making rights
 2. provide information to persons during legal proceedings
 3. help people to make and communicate their decisions
 4. explain the nature and implications of the proceedings
5. Legal standing for support persons
6. A monitor

British Columbia example

- Representation Agreements must be concluded in front of witnesses: if the agreement is not completed with a lawyer, then two witnesses are required.
- A **monitor** is appointed - for ongoing financial affairs. The monitor has a specific role. The monitor is there to ensure that the representative fulfils his/her duties. Monitors can also provide support and help resolve problems if necessary, and the law states that nothing can prevent them from having contact with the adult in question.

The key principles (i)

- The provision of support to exercise legal capacity should not hinge on mental capacity assessments; **new, non-discriminatory indicators** of support needs are required in the provision of support to exercise legal capacity.

Discussion

Your questions!

Thank you for your attention!

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Education and Employment



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Introduction

Education and employment

- Economic and social rights
- Mutually strengthening

Content

- Education
- Employment

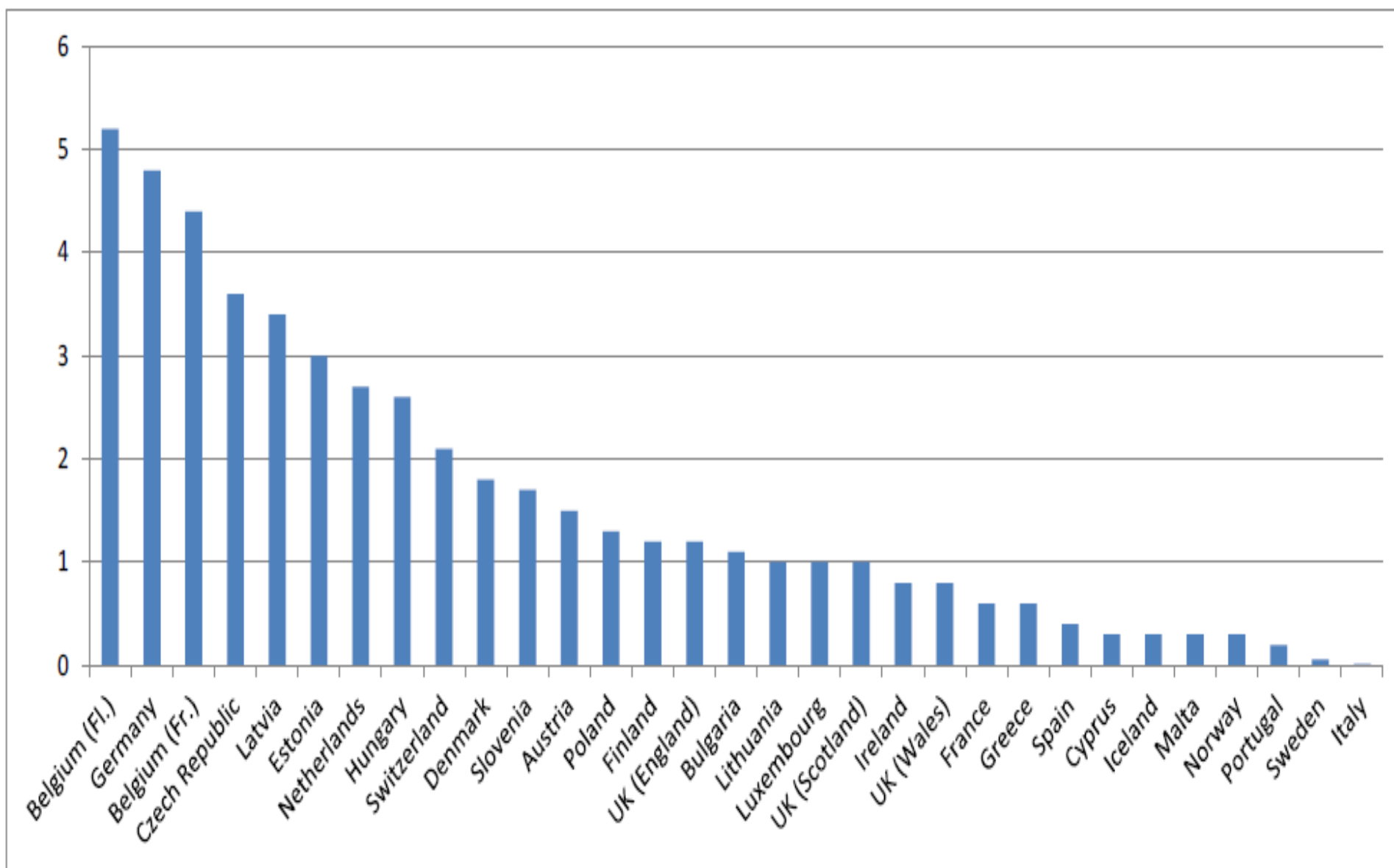
Education

Right to education of disabled people

Pre-CRPD

- ❑ UDHR
- ❑ ICESCR
- ❑ Standard Rules on the Equalization of Opportunities for Persons with Disabilities
- ❑ Salamanca Statement and Framework for Action on Special Needs Education

Figure 2: Number of pupils in segregated special schools as a percentage of total pupil population in selected European countries



Education

Article 24

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning ...

Principle = inclusive education

Education

2. In realizing this right, States Parties shall ensure that:

(a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

(b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

(c) Reasonable accommodation of the individual's requirements is provided;

(d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

...

Education

(e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

...

4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

Education

Obligations:

- ❑ Non-discrimination (including the duty to provide reasonable accomodation)
- ❑ Progressive realisation
 - Accessibility
 - (Individualised) support
 - Teacher education
 - Promotion

Education

Inclusive Education Systems

- ▣ Adapted curriculum, methods and assessment
- ▣ Welcoming school environments

Universal Design in Education

Education

Special schools?

- Transition period
- Blind, deaf and deaf-blind children

No segregation

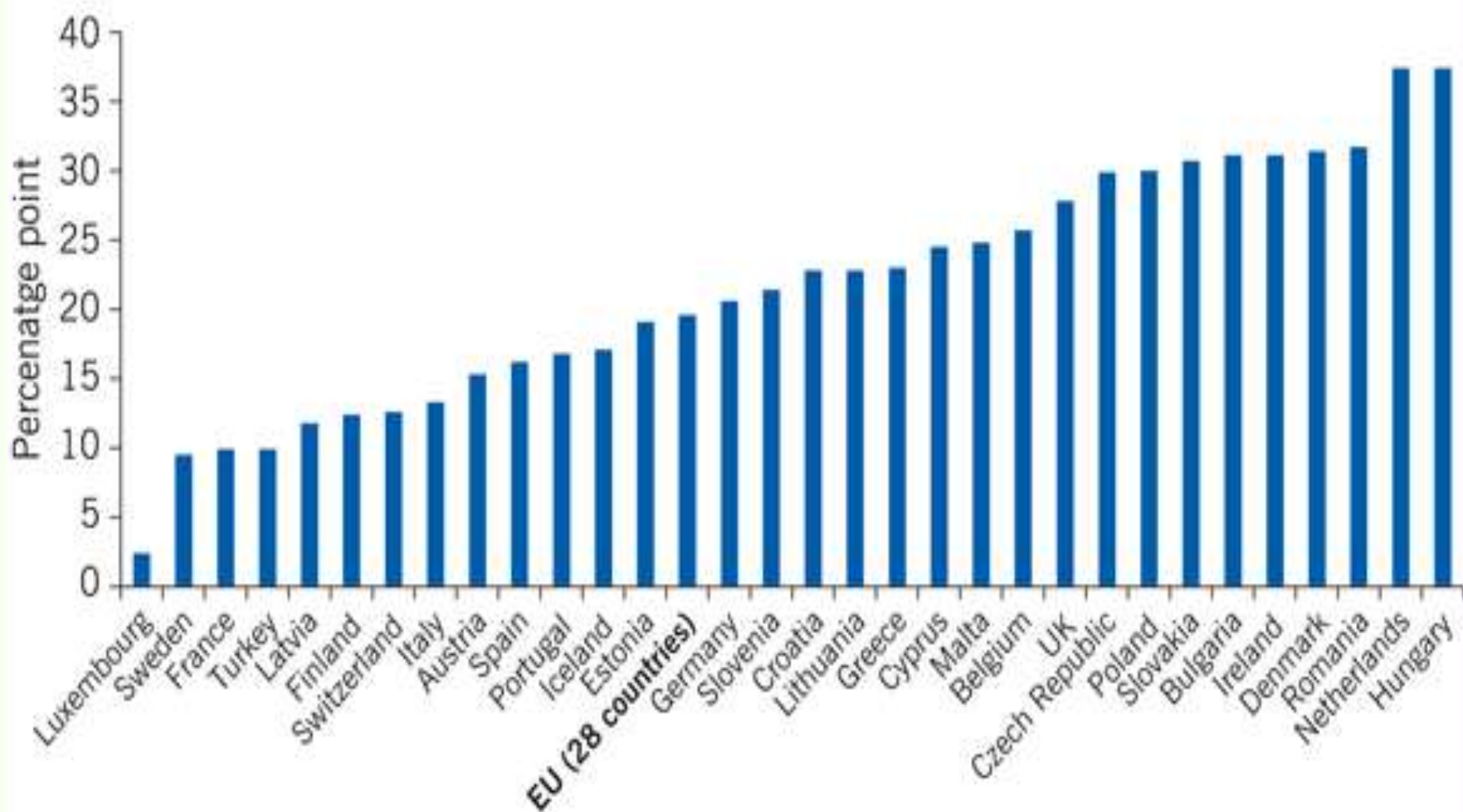
Employment

Right to work of disabled people

Pre-CRPD

- ❑ UDHR
- ❑ ICESCR
- ❑ Vocational and Rehabilitation and Employment (Disabled Persons) Convention
- ❑ Standard Rules on the Equalization of Opportunities for Persons with Disabilities

Figure 2. Gap in the employment rate between those who do and do not report disability (aged 15–64)



Note: "Disability" is defined as long-standing difficulties in basic activities.

Source: European Union Labor Force Survey (EU-LFS), 2011.

Employment

Article 27

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.

...

Principle: open labour market

Employment

... States Parties shall safeguard and promote the realization of the right to work ... by taking appropriate steps ... to, inter alia:

(a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;

(b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;

(h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;

(i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;

...

Employment

Obligations

- ❑ Non-discrimination (including duty to provide reasonable accommodation) – recruitment, salary, promotion, training and so on
- ❑ Progressive realisation
 - Accessibility
 - Continuing training
 - Professional rehabilitation
 - Promotion

Employment

Sheltered Workshops?

- Exception
- Conditions (European Committee of Social Rights)
 - Persons with disabilities who are not able to work in the open labour market
 - Transition towards open labour market
 - Application of labour laws

Strict application

Employment

European Union

EU Law

- ❑ Article 19 of the Treaty on the Functioning of the European Union (TFEU)
- ❑ Directive 2000/78/EC
 - Religion or belief, disability, age or sexual orientation in the areas of employment and occupation
 - Duty to provide reasonable accommodation to disabled people

Employment

Case law

- *Chacón Navas*
- *Coleman*
- *Ring and Skouboe Werge*
- *Kaltoft*

Employment

Challenges

- ❑ Limited to employment and occupation
- ❑ What is a disability?

Luxembourg “hammer of justice” of the CRPD

Resources

Articles

- ❑ de Beco, G., 'Is Obesity a disability? The Definition of Disability by the Court of Justice of the European Union and its Consequences for the Application of EU Anti-Discrimination Law' (2016) 22 (2) *Columbia Journal of European Law* 381-401.
- ❑ de Beco, G., 'Transition to Inclusive Education Systems According to the Convention on the Rights of Persons with Disabilities' (2016) 34 (1) *Nordic Journal of Human Rights* 40-59.
- ❑ de Beco, G., 'The Right to Inclusive Education According to Article 24 of the UN Convention on the Rights of Persons with Disabilities: Background, Requirements and (Remaining) Questions' (2014) 32 (3) *Netherlands Quarterly of Human Rights* 263-287.
- ❑ de Beco, G., 'Le droit au travail des personnes handicapées en vertu de l'article 27 de la Convention des Nations Unies relative aux droits des personnes handicapées, avec application en Flandre' (2013) (4) *Revue belge de sécurité sociale* 563-585.

Conclusion

Thank you for your attention!

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Accessibility

Alejandro Moledo, EDF New Technologies and Innovation officer
EU DISABILITY LAW AND THE UNCRPD, Trier, 24 May 2016

About the European Disability Forum

- Umbrella organisation
- 80 million Europeans with disabilities in Europe (15% EU population)
- Organisation OF persons with disabilities, RUN BY persons with disabilities
- Fight against discrimination and promote the Human Rights of persons with disabilities
- Advocacy organisation at European level
- Closely work with the EU, the Council of Europe and the UN

Twin-Track Advocacy Approach

**Disability Specific
(empowerment)**

**Societal
(mainstreaming disability)**

- Network organisation – over 100 members
- Regular collaboration with policy-makers, industry and standards bodies, and other users' organisations

Why accessibility?

- Material basis to benefit from the Human Rights enshrined in the UN CRPD
- Link between accessibility and non-discrimination
- Soft approach to accessibility failed
- Accessibility is not sufficiently addressed in national legislations
- Legislation is essential and standards are needed
- Labels and raising awareness can help
- Enforcement, monitoring and redress mechanism are essential

Accessibility...

is not a black/white issue !

And it is not a backyard entrance

Global, horizontal and holistic

Allowing the use of assistive technologies

Beneficial to everybody

More cost-effective when incorporated from the outset

ACCESSIBILITY MINDSET

UN CRPD & Accessibility

Accessibility as General Principle (Article 3.f)

- To interpret the whole UNCRPD
- Precondition to enjoy the rights

EDF's definition:

"Accessible' means a good, service, site, technology (including information and communication technologies and systems), procedure, or physical and built environment which is easy to approach, enter, exit, operate, participate in and use safely, independently, and with dignity by a person with a disability or reduced mobility under all circumstances (including emergency cases). This does not exclude the use of assistive devices or augmentative and alternative communication systems to achieve accessibility for particular groups of persons with disabilities where this is needed."

Article 9. Accessibility

- States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others
 - Physical environment
 - Transportation
 - Information and Communication, including ICT & systems
 - Other facilities and services provided to the public
 - schools, housing, medical facilities and workplaces)
 - Electronic services and emergency services

[1st International Human Rights Treaty
addressing ICT]

Article 9. Accessibility

Other measures:

- Standards and guidelines
- Private entities
- Trainings
- Use of Braille and easy-to-read
- Intermediaries for communication, e.g. sign language interpreters
- Alternative formats
- ICT & systems, “including the Internet”
- Promote the accessible ICT “at an early stage, so that these technologies and systems become accessible at minimum cost”

UN CRPD Committee General Comment n° 2

- Public and private alike
- Accessibility standards
- Barriers to be removed gradually with continuous monitoring
 - costs shall not be an excuse
 - Timeframes, resources and responsible authorities
- Increase the involvement of persons with disabilities in the designing stage, including in accessibility standards' development

UN CRPD Committee General Comment n° 2

Accessibility:

- Groups
- Ex ante duty
- Accessibility standards
- Unconditional

Reasonable Accommodation:

- Individuals
- Ex nunc duty
- May be out of any standard
- Undue burden

UN CRPD Committee General Comment n° 2

States Parties obligations:

- Adopt a suitable legal framework based on the universal design principle
- Develop accessibility standards in consultation with persons with disabilities also through international cooperation
- Mandatory application of accessibility standards, including fines
- Public procurement policies

Universal Design / Design for All

UN CRPD definition: “means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. “Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.”

Universal Design Principles

- Equitable use
- Flexibility in use
- Simple and intuitive use
- Perceptive information
- Tolerance for error
- Low physical effort
- Size and space for approach and use

“To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and **to promote universal design in the development of standards and guidelines**”

UN CRPD Article 4.1(f). General obligations

European Standardisation System (ESS)

- [Regulation 1025/2012](#)
- Recital 19: “standards can contribute ... to the inclusion of persons with disabilities”
- Recital 24: the ESS should take into account the UN CRPD
- Accessibility not enforced
- No DPO as Annex III organisation (societal stakeholders eligible to be funded by the Commission)

European Standardisation System (ESS)

‘standard’ means a technical specification, adopted by a recognised standardisation body, for repeated or continuous application, with which compliance **is not compulsory**, and which is one of the following:

- ‘international standard’ means a standard adopted by an international standardisation body;
- ‘European standard’ means a standard adopted by a European standardisation organisation;
- ‘harmonised standard’ means a European standard adopted on the basis of a request made by the Commission **for the application of Union harmonisation legislation**;
- ‘national standard’ means a standard adopted by a national standardisation body;

Barriers and solutions in Standardisation for DPOs

Barriers:

- Limited funding opportunities
- Lack of accessible environment
- High level of expertise and skills required
- Lack of influence

Solutions:

- Offering new funding opportunities
- Developing capacity-building activities and tools
- Policy actions
- Inclusive procedures (best example: SIS - Sweden)
- [ISO/IEC Guide 71](#), 2014 “for addressing accessibility in standards”

Key Commission Mandates

- [Mandate 376](#): to CEN, CENELEC and ETSI in support of European accessibility requirements for public procurement of products and services in the ICT domain
- [Mandate 420](#): to CEN, CENELEC and ETSI in support of European accessibility requirements for public procurement in the built environment
- [Mandate 473](#): to CEN, CENELEC and ETSI to include “Design for All” in relevant standardisation initiatives

EN 301 549 V1.1.1 (2014-02)



Accessibility requirements suitable for public procurement of ICT products and services in Europe

Why is this standard important?

- 1st European Standard on e-Accessibility
- Technical specifications for equal access to ICT:
 - **websites, emails, documents, books, videos, communication devices, ATMs, self-service machines...**
- Public Procurement Directive: accessibility requirement for technical specifications ([article 42](#))
- Potential Harmonised Standard to prove compliance with the future Web Accessibility Directive and EAA
- Relationship with the US Rehabilitation Act Section 508 (under [revision](#)) and other international standards
- All the information is available in the [EDF Toolkit for the promotion of the EN 301549](#)

Content:

- Scope
- Definitions and abbreviations
- Functional performance (informative)
- Generic requirements:
 - ICT with two-way voice communication
 - ICT with video capabilities
 - Hardware
 - Web = WCAG 2.0 Level AA = ISO 40500;2012
 - Non-web documents
 - Non-web software
 - Documentation and support services
 - ICT providing relay or emergency services
- Annex A: WCAG 2.0
- Annex B: Relationship between requirements and functional performance statements
- Annex C. Determination of compliance (normative)

Example

5. Generic requirements

5.1 Closed functionalities

5.1.3 Non-visual access

5.1.3.1 General

Where visual information is needed to enable the use of those functions of ICT that are closed to assistive technologies for screen reading, ICT shall provide at least one mode of operation using non-visual access to enable the use of those functions.

- *NOTE 1: Non-visual access may be in an audio form, including speech, or a tactile form.*
- *NOTE 2: The visual information needed to enable use of some functions may include operating instructions and orientation, transaction prompts, user input verification, error messages and non-text content.*

Example

C.5.1.3 Non-visual access

Type of compliance	Testing
Pre-conditions	1. Visual information is needed to enable the use of those functions of the ICT that are closed to assistive technology for screen reading.
Procedure	1. Determine the functions of the ICT closed to screen reading. 2. Check that they are all operable using non-visual access.
Result	Pass: Check 2 is true Fail: Check 2 is false

Final remarks about standards

- Increasing importance at EU level
- Standards are the means to a goal, not the goal itself
- In support of legislation (not the way around)
- Minimum level of accessibility, but we should go beyond
- Allow innovation and competition



THANK YOU

For more information please contact EDF Secretariat:
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e-Accessibility

Alejandro Moledo, EDF New Technologies and Innovation officer
EU DISABILITY LAW AND THE UNCRPD, Trier, 24 May 2016

ICT as key enabler for persons with disabilities

- Gateway to social participation and independent living
- Mainstream and assistive technologies
- Overcome existing barriers
- More easily adaptable

**Accessibility an intrinsic element of ICT,
similar to others (privacy, data protection, etc.)**

ICT as key enabler for persons with disabilities

Triple A (available, affordable and accessible)

ITU – “The ICT opportunity for a disability-inclusive development framework” ([here](#))

- **Web**
- **Mobile**
- **Audiovisual media**

Barriers:

- Cost of assistive technologies
- Lack of accessible ICT goods and services

Digital Single Market Strategy, 2015

[Read the DSM strategy](#)

- 16 actions to harmonise the rules of the Internal Market in the digital environment
- Lack of inclusive approach
- Opportunities for persons with disabilities:
 - Audiovisual Media Services Directive
 - Universal Services Directive
 - e-Commerce Directive
 - e-Skills, etc.
 - e-Government Action Plan

EDF & AGE Platform recommendations for an Inclusive Digital Single Market

- **One in three persons with disabilities has never used the internet**, which represents 54% of those who have never been online.
- **Over 69% of people who lack basic digital skills are aged over 55.**
- There is still **much room for improvement** with regards to accessibility of websites (less than a third are accessible), equal access and choice in telecommunications products and services (huge variations across the EU), and in the accessibility of audiovisual content

Web Accessibility

UN CRPD Article 21 on Freedom of expression:
“Urging **private entities** that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
Encouraging **the mass media**, including providers of information through the Internet, to make their services accessible to persons with disabilities;”

What do we mean by web accessibility?

[EDF e-resource on web accessibility](#)

Web Accessibility Principles

A website shall be:

- Perceivable
- Operable
- Understandable
- Robust

Guidelines

[W3C Web Content Accessibility Guidelines 2.0](#)

Success criteria (testable): Level A, AA, AAA

Benefits of web accessibility

- Equal opportunities for persons with and without disabilities
- Faster loading time
- Increased usability
- Reduced site development and maintenance time
- Better search engine indexation
- Wider compatibility
- Inclusive digitalisation
- Legal compliance

**REQUIRE AT LEAST LEVEL AA
STRIVE FOR LEVEL AAA (OR BEYOND)**



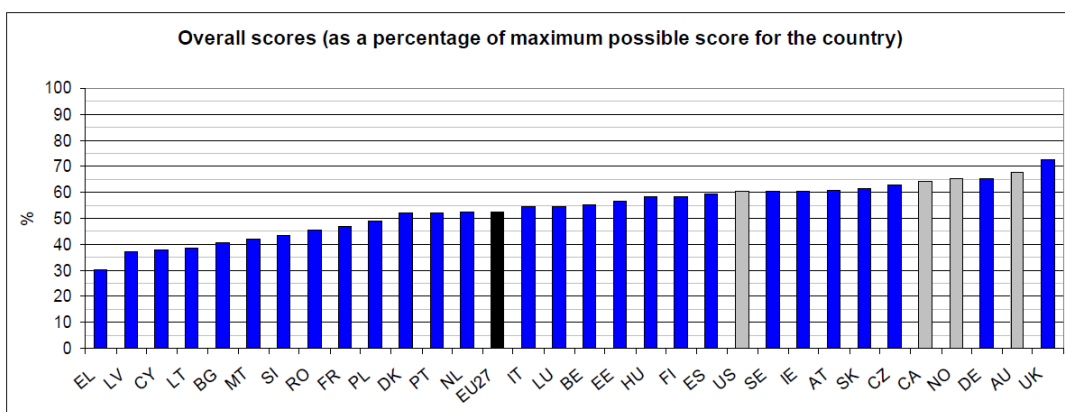
THE UNITED STATES
DEPARTMENT OF JUSTICE

Justice Department Enters into a Settlement Agreement with Peapod to Ensure that Peapod Grocery Delivery Website is Accessible to Individuals with Disabilities

November 17, 2014. The Justice Department announced today that it has entered into a settlement agreement with Ahold U.S.A. Inc. and Peapod LLC, the owners and operators of www.peapod.com, to remedy alleged violations of the Americans with Disabilities Act (ADA). Peapod is America's leading Internet grocer, delivering more than 23 million orders in 12 Midwest and East Coast states and the District of Columbia. The agreement resolves the department's allegations that www.peapod.com is not accessible to some individuals with disabilities, including individuals who are blind or have low vision, individuals who are deaf or hard of hearing, and individuals who have physical disabilities affecting manual dexterity.

Continue reading the news: <http://www.justice.gov/opa/pr/justice-department-enters-settlement-agreement-peapod-ensure-peapod-grocery-delivery-website>

Meanwhile in Europe...



Source: "Study on assessing and promoting e-accessibility", available at: <http://ec.europa.eu/digital-agenda/en/news/study-assessing-and-promoting-e-accessibility>

Meanwhile in Europe...

Overall scores (as percentage of maximum possible score for the type of service)

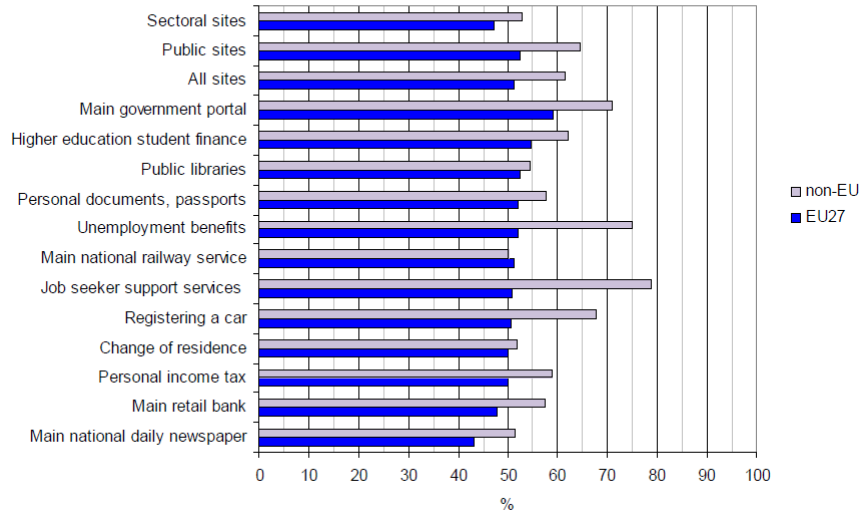


Figure 2-36 Accessibility scores for tests related to modern design approaches - public sites

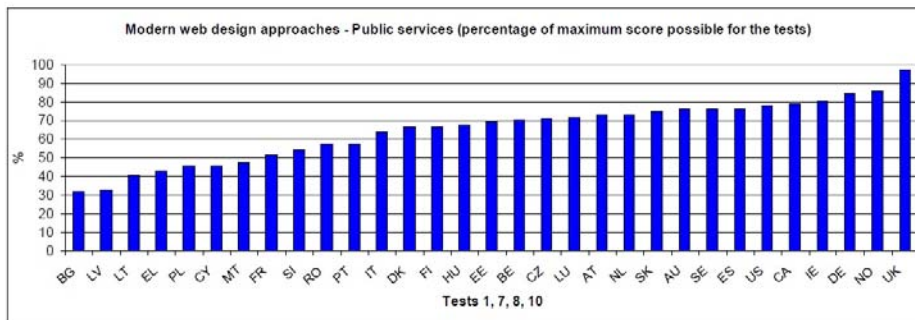
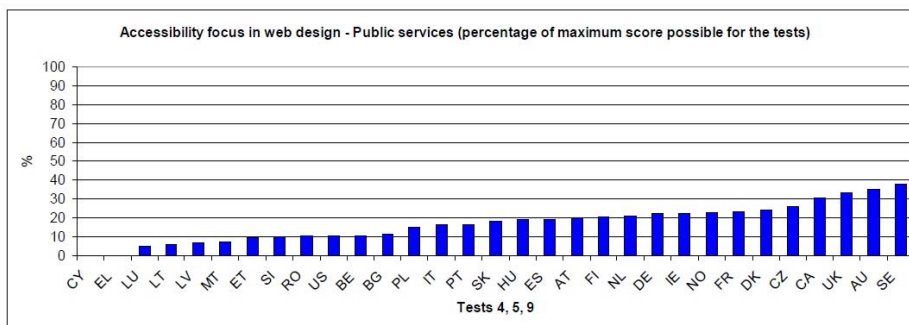


Figure 2-37 Accessibility scores for tests for a specific accessibility focus in the design - public sites



Conclusions MeAC 3

- Progress in recent years
- Countries with strong obligations + monitoring obligations score better
- Huge variation across the EU
- WCAG 2.0 level AA with some variations
- Focused on blind users

Other resources: [EIII project](#) (benchmarking), [WAVE](#) (automatic tool), Study "[Measures to improve accessibility of public websites in Europe](#)"

Proposal for a Directive on the Accessibility of Public Sector Bodies' Websites

European Commission:

- 12 types of websites
- No enforcement body
- Monitoring
- Reporting annually

[EDF campaign on Web Accessibility](#)

European Parliament:

- All public sector bodies' websites + services of general interest (annex)
- Apps + Authoring tools
- Enforcement body
- Monitoring and reporting
- Penalties
- Expert group at EU level
- Involvement of persons with disabilities
- Gradual implementation

NEW! Agreement on the web accessibility Directive

- All public sector bodies websites and mobile apps (Public Procurement Directive definition)
- Digital documents and online services
- Exceptions:
 - broadcasters
 - live audiovisual – to be made accessible in 14 days
 - Non-administrative functions of schools, kindergartens and nurseries' websites
- Disproportionate burden
- Web accessibility statement, including feedback mechanism with an on-demand service for inaccessible content

NEW! Agreement on the web accessibility Directive

- Use of harmonised standard (web and mobile) – in absence of it: Common Technical Specifications for mobile
- Enforcement mechanism:
 - National authority with a complaint mechanism
 - Focal point for web accessibility (trainings, materials, contact with users' organisations, etc.)
- Regular monitoring (check [study on monitoring methodologies for web accessibility](#))
- Reporting to the Commission
- Implementation – 21 months for transposition:
 - +12 months for new websites
 - +24 months for existing websites
 - +33 months for mobile apps

Telecoms

UN CRPD Article 9 on Accessibility:
“Information, communications and other services,
including electronic services and emergency services”

The EU framework

- The [Framework Directive](#) is based on the [Framework Directive 2002/21/EC](#) and the [Better Regulation Directive 2009/140/EC](#)
- The [Access Directive](#) is based on the [Access Directive 2002/19/EC](#) and the [Better Regulation Directive 2009/140/EC](#)
- The [Authorisation Directive](#) is based on the [Authorisation Directive 2002/20/EC](#) and the [Better Regulation Directive 2009/140/EC](#)
- The **Universal Service Directive** is based on the [Universal Service Directive 2002/22/EC](#) and the [Citizens' Rights Directive 2009/136/EC](#)
- The [Directive on Privacy and Electronic Communications](#) is based on the [Directive on Privacy and Electronic Communications 2002/58/EC](#), the [Amending Directive 2006/24/EC](#) and the [Citizens' Rights Directive 2009/136/EC](#)
- The [Regulation on Body of European Regulators for Electronic Communications \(BEREC\)](#)
- The [Regulation on roaming on public mobile communications networks](#)

The EU framework

2009 revision – success of the disability movement

- Good example of mainstreaming disability in EU legislation
- Follows the UN CRPD

Article 23a of the Universal Service Directive

Equal access and choice to, and affordability of:

- **Electronic communication services “equivalent to that enjoyed by the majority of endusers”**
- **Terminal equipment**

“Study on assessing and promoting e-Accessibility” (MeAC 3)

November 2013

27 Member States + 4 non-EU countries (US, CA, NO, AU)

- accessible directory services,
- payphones
- provision of relay services (text and video)
- provision of special equipment.
- emergency services

Figure 3-1 No of countries with any provisions concerning accessibility of directory services (n=31)

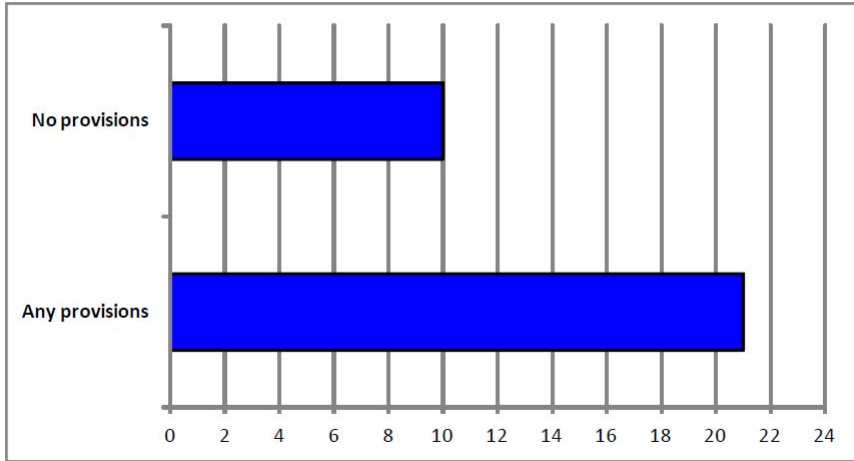


Figure 3-2 No. of countries with provision of any accessibility features with public pay phones (n=31)

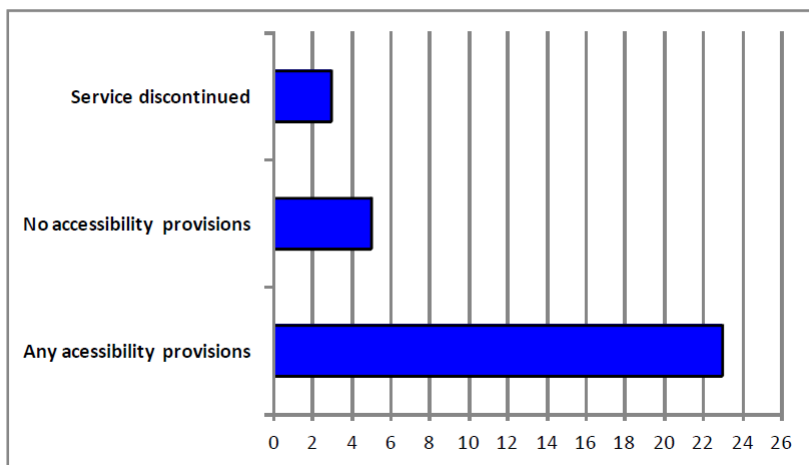


Figure 3-3 No. of countries in which a relay service is available (n=31)

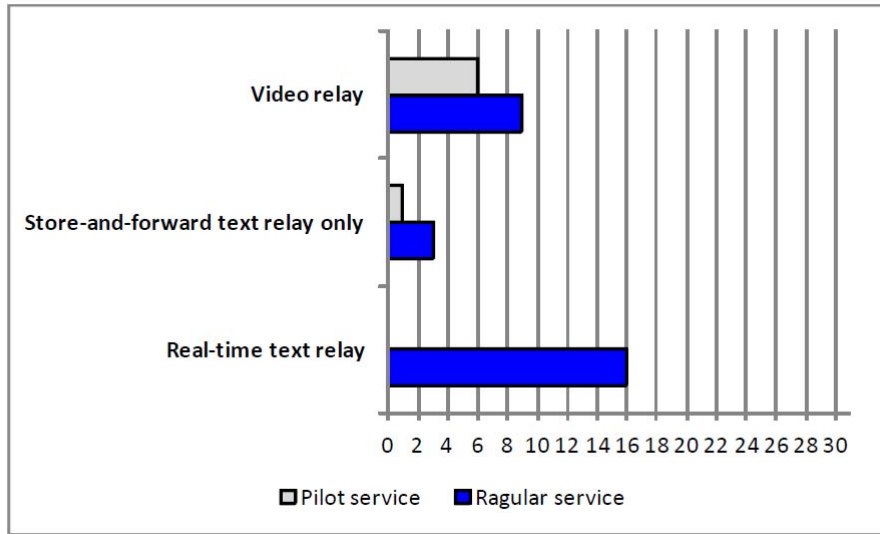
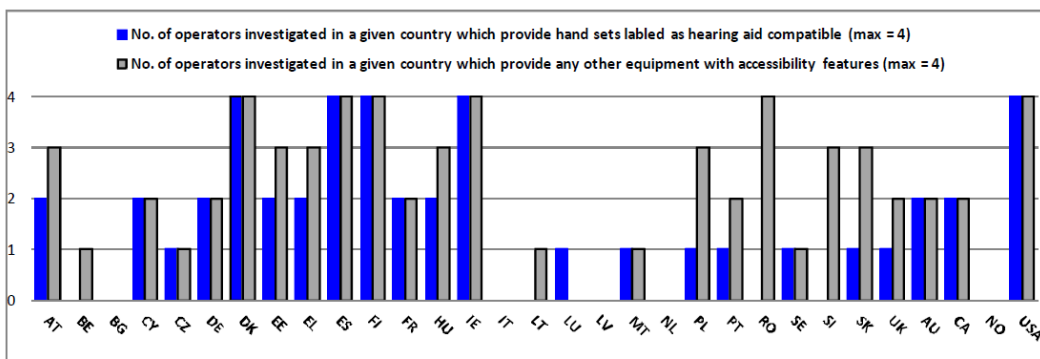
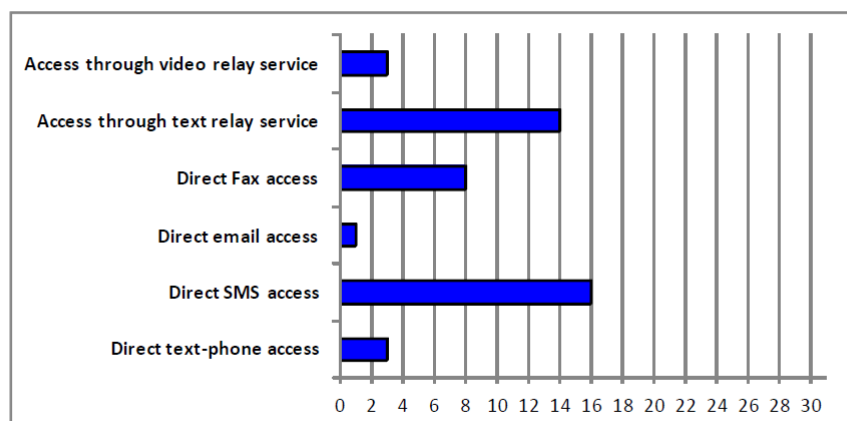


Figure 3-5 No. of telecoms operators offering accessible end user equipment per country



Note: The two main fixed line operators and two mobile operators were investigated in each country.

Figure 3-6 No. of countries where access to emergency services is provided by alternative communication modes (n=31)



Note: More than one access option may exist in a given country

MeAC 3 conclusions:

- Progress in recent years
- Room for improvement in both access and choice
- Considerable variation across Member States

[BEREC - 2015 report on equal access and choice](#)

Barriers encountered by EDF members:

- Lack of interoperability and common approach (RTT, emergency services, etc.)
- Persons with disabilities living in remote areas – less choice of accessible services and/or not aware of their availability
- Products and services for persons with disabilities are procured outside the mainstream procurement of products and services
- Lack of involvement of organisations representing persons with disabilities in the NRA's
- Some NRA's too business-oriented
- Non-accessible information, e.g. websites of Telecoms providers – no requirement by NRA's
- NRA's lack of guidance for users and providers in understanding accessibility provisions
- Lack of monitoring on accessibility

EDF Recommendations:

To NRA's:

- Refer to the **EN 301 549**: web, software, documents, ICT with two-way voice communication, ICT with video capabilities, ICT providing relay or emergency services, etc.
- Add conditions to the general authorization to deliver e-communication services
- Ensure a wide definition of terminal equipment intended for PwD
- Place requirements to all communication service providers, including new ways of communication (e.g. mobile apps)
- Provide guidance to users and companies
- Involve persons with disabilities
- Regular monitoring
- Raise awareness of the accessibility provisions adopted in the country

EDF recommendations:

At EU level:

- Ongoing mechanism to provide guidance to NRA's
- Enhance interoperability and common approach (especially on 112)
- Regular and harmonised benchmark reporting exercise both on access and choice – publicly available and in accessible formats
- Involve users' organisations in BEREC Working Groups
- Raise awareness on the rights of EU citizens concerning accessibility on e-communications

Related documents:

- [UN CRPD](#), and [General Comment No. 2 – Article 9](#)
- [EDF presentation at the BEREC Accessibility Workshop](#), October 2013
- [EDF Position on Indicators to Check and Assess Accessibility of Telecommunications for Persons with Disabilities](#), April 2012
- [EDF Toolkit on the Telecoms Package](#), September 2011
- [ANEC/EDF Answer to the BEREC public consultation on Electronic Communications Services: Ensuring Equivalence in Access and Choice for Disabled End-Users](#), November 2010

New documents will be upload very soon

Audiovisual

UN CRPD Article 30 on Participation on cultural life:
“Enjoy access to television programmes, films, theatre
and other cultural activities, in accessible formats”

Accessibility for audiovisual services

Access services

- Captions (closed & live)
- Sign Language interpretation
- Audio description
- Spoken subtitles
- Clean Audio
- Usability & quality issues
- 2nd screen / 2nd device solutions

Audiovisual Media Services Directive ([here](#))

- Adopted in 2007
- TV broadcasting + on demand services (VOD)
- Operators established in the EU
- Commercial communications
- User protection and prohibition of hate speech and discrimination
- Protection of minors
- Promote EU audiovisual content
- Coordination of regulators

Audiovisual Media Services Directive ([here](#))

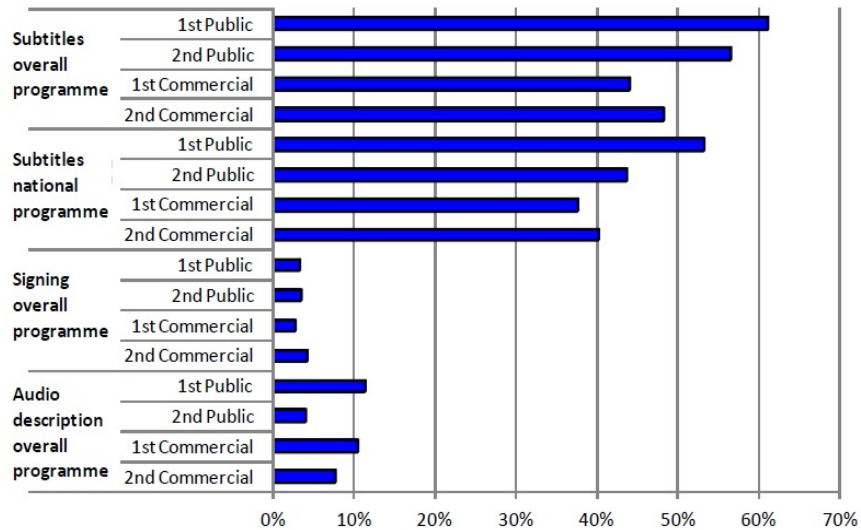
Recital 46: (...)The means to achieve accessibility should include, but need not be limited to, sign language, subtitling, audio-description and easily understandable menu navigation

Article 7. “Member States shall **encourage** media service providers under their jurisdiction to ensure that their services are gradually made accessible to people with a visual or hearing disability”

Article 9.c(ii): anti discrimination on the grounds of disability in commercial communications

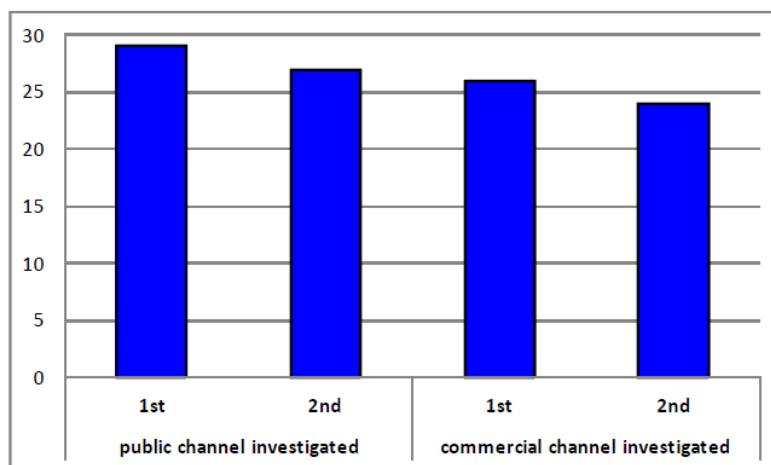
MeAC 3 study – November 2013

Figure 4-2 Average share of programmes with access services in the overall programme across all countries included in the study



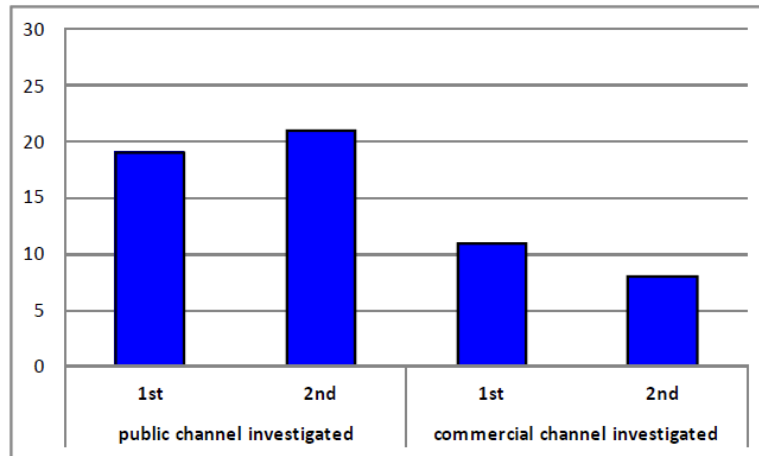
MeAC 3 study

Figure 4-1 No. of countries with any subtitling (n=31)



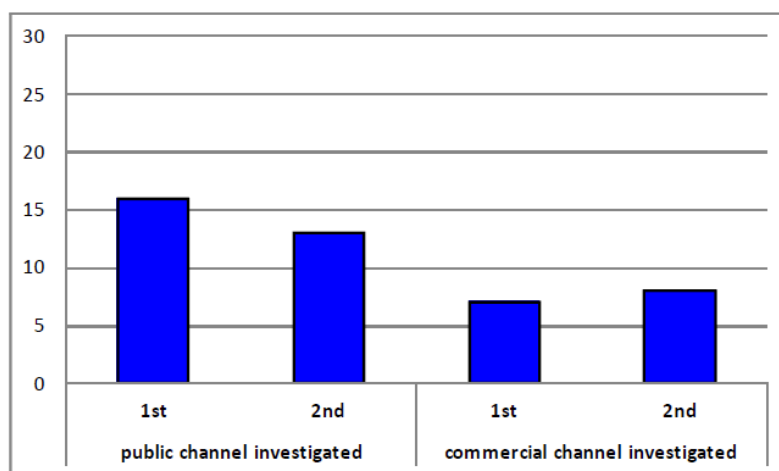
MeAC 3 study

Figure 4-3 No of countries with any signing (n=31)



MeAC 3 study

Figure 4-4 No. of countries with any audio description (n=31)



What is the overall situation?

- Implementation of art. 7 differs broadly
- Only 9 countries provide the three basic access services
- Commercial channels lagging behind
- Video on-demand less accessible
- Electronic Programme Guides (EPG) inaccessible
- Online platforms not enabling access services
- More devices enabling access services but no accessible content to render

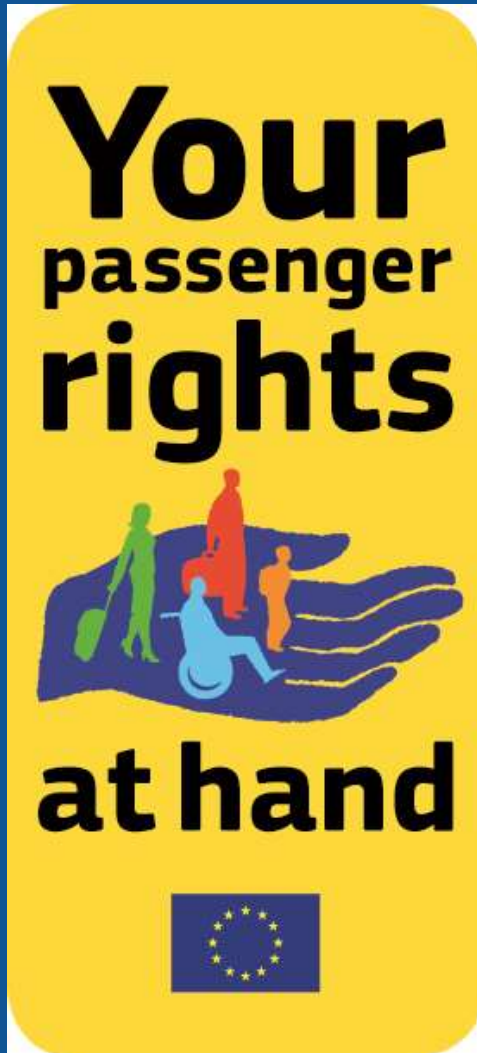
EDF answer to the public consultation on AVMS Directive

- Access services *for all*
- Commercial broadcasters too
- Set up binding gradual quantitative targets of access services to all TV-like providers (broadcasters and VOD)
- Make not-TV-like providers support access services
- All operators targeting EU audience must be included
- Include disability in the anti-discrimination article
- Quality standards
- EPG accessible and informing about access services
- Complaint, reporting and monitoring mechanism
- Involve users!



THANK YOU

For more information please contact EDF Secretariat:
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EU Passenger Rights Legislation and the UN Convention on the Rights of Persons with Disabilities

**Ruth Lopian,
European Commission
DG MOVE – Passenger Rights Unit
ERA Trier, 23 – 24 May 2016**



Introduction

1. *EU Legal Framework for Persons with Disabilities*
2. *EU Passenger Rights Legislation*
3. *Awareness raising*
4. *Application of EU Passenger Rights Legislation*
5. *Key concerns and guidance*
6. *Recent and planned developments*

EU legal framework – Persons with disabilities

- *Art. 10 TFEU (EU Treaty)*
non-discrimination
- *EU Charter of Fundamental Rights:*
non-discrimination, integration of persons with disabilities ⇒ mandatory for EU institutions and MS when implementing EU law
- *UN Convention on the Rights of persons with Disabilities:*
⇒ ratified by EU and its MS
Article 9 – Accessibility
Article 20 - Personal mobility
- *European Disability Strategy 2010-2020 :*
Accessibility = one of the main areas for action
- *European Accessibility Act:*
Commission Proposal of 2/12/2015 - Includes a set of standards on accessible transport infrastructure (eg. ticketing, check-in, real-time travel information, websites etc.)

EU Legal framework – Passenger rights legislation

Rights of disabled persons and persons with reduced mobility using transport services:

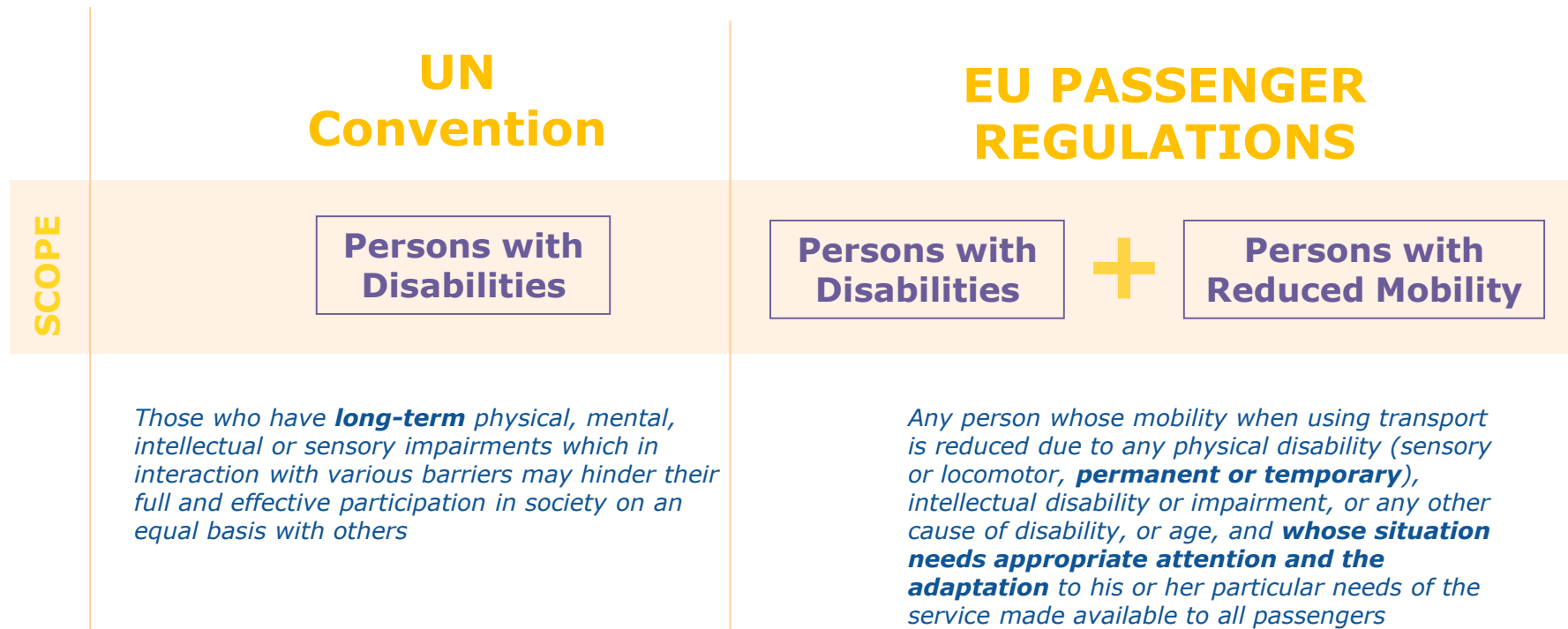
- [Regulation \(EC\) No 1107/2006](#) concerning the rights of disabled persons and persons with reduced mobility when travelling by **air**
- [Regulation \(EC\) No 1371/2007](#) on **rail** passengers' rights and obligations
- [Regulation \(EC\) No 1177/2010](#) concerning the rights of passengers when travelling by **sea** and **inland waterway**
- [Regulation \(EC\) No 181/2011](#) concerning of passengers in **bus** and **coach** transport

Related normative acts:

- [Commission Regulation No 1300/2014](#) on interoperability specifications in the railway sector (PRM-TSI)
- [Directive 2009/45/EC](#) on safety rules and standards for passenger ships
- [Directive 2001/85/EC](#) on special provisions for vehicles used for the carriage of passengers comprising more than eight seats in addition to the driver's seat , repealed by [Regulation \(EC\) No 661/2009](#) of the European Parliament and of the Council of 13 July 2009

Definition

EU Passenger Regulations: beyond the disability



Scope and Objectives of Passenger Rights Legislation

1. Protect PRMs against **discrimination**:
 - Prohibition to refuse booking or embarkation due to disability/reduced mobility. Tickets shall be offered at no additional cost
 - Derogation only for reasons of safety or design of the vehicle
2. Ensure that PRMs receive professional and seamless **assistance** so that they can travel
3. **Accessibility**:
 - For air, waterborne and bus & coach: only some soft accessibility aspects (in recitals),
 - PRM TSI in rail,
 - Provisions on accessible information

Principles

- The **managing body** of an airport/port/rail and coach station shall be responsible to provide assistance up to seats inside the vehicle/ship/plane
- **Carriers** are mainly responsible for allocating seats in order to meet passenger needs and the carriage of mobility equipment, plus assistance to move inside the vehicle/ship/plane if necessary/feasible
- No ***opt-out*** for carriers – but infrastructure managing bodies can subcontract for the supply of assistance
- Assistance **without additional charge** to PRMs

Assistance – General principles

- PRMs to notify need for assistance to carriers, their agents, tickets sellers or tour operators [if no notification: only best efforts]
- Carriers/undertakings receive notification at least **48** hours (maritime, rail, aviation) or **36** hours (coach) before departure time and transmit info to managing bodies
- Recognised assistance dogs to be accommodated in accordance with national rules (air).

Assistance

- Obligation to designate points of arrival and departure for start/end of assistance
- For coach, obligation to designate accessible stations. List published by the Commission on the Internet
- PRMs to present themselves at check-in:
 - at the time stipulated by the carrier, or
 - not later than 60m or 30m (coach) before departure time
- Airports/port terminals shall set quality standards for the assistance; *Exemptions:*
 - airports <150.000 commercial passenger/year,
 - ports <100.000 passengers/year (to be published in internet)

Accessibility and information

- Carriers, rail operators and terminal/stations operators shall have in place **non-discriminatory access conditions**
- The access conditions shall be made **publicly available**
- Information on **conditions of carriage, journey conditions and access conditions** are to be made available in appropriate and accessible formats for disabled persons and PRM (“where feasible” for coach)
- **Confirmation of assistance** by any means available including sms (maritime).

Compensation in respect of mobility equipment

- Carriers and terminal operators/managing bodies are **liable for loss or damage**, if the incident was due to their fault or neglect, in accordance with EU, national or international law:
- **Compensation** = replacement value or repair costs.
 - *Aviation: strict liability under Montreal Convention.*
 - *Maritime: does not apply when Regulation 392/2009 applies (Liability of carriers of passengers by sea in the event of accidents).*
 - *Rail: no financial limitation to the replacement/repair costs.*
- Every effort must be undertaken to provide **temporary replacement equipment**

Training

- Disability-related training procedures depending on role of staff for aviation, maritime and coach (no obligations in rail)
- Training to be provided both to staff of the infrastructure management and of the transport carriers/undertakings
- For **coach**, MS may for a maximum period of 5 years from 1 March 2013, grant an exemption with regard to training of drivers
- For **rail**, a quality management system shall be set up



Complaint handling and enforcement

- Complaint handling mechanisms by carriers (and airports)
- Member States designate national enforcement bodies (NEBs)
- Passengers can complain to NEBs
- Member States provide for sanctioning schemes for infringements of the Regulations

INFORMATION CAMPAIGNS



- **Campaigns between 2010 and 2015** (website, posters, leaflets, videos, local events...)
- **NEW Campaign in 2016-2017:**
 - Focus on digital communication tools (SmartApps, Facebook, Instagram, Twitter...)
 - Engage stakeholders (e.g. PRM associations, transport companies) to disseminate information via their own digital communication channels
 - Targeted to transport hubs or destinations

Application of EU Passenger Rights Legislation

Application of Regulation 1107/2006 (Report in 2011):

- Two studies on the implementation of Regulation (EC) 1107/2006 to
 - evaluate the functioning of the Regulation in general
 - look at the penalties applied in Member States to violations of the Regulation
- **Main findings:**
 - overall, travel experience of PRM travellers has improved **but**
 - variable interpretation of rules in MS and by the air transport industry
 - Inconsistent application

Application of Regulation 1371/2007 (Report in 2013):

- Study in 2012
- **Main findings:**
 - overall, good application of the Regulation by all actors **but**
 - Problems for PRM travellers mainly owing to **national exemptions**

Key concerns regarding the application of Regulation 1107

- *(low levels of) Pre-notification*
 - *Denied boarding situations based on inconsistent requirements for medical certificates and for passengers to be accompanied*
 - *Problems with medical and mobility equipment*
- Fundamental principle of safety on board**

Clarification provided by the 2012 Guidelines on PRM APR

- *Definitions*
- *Derogations, special conditions and information*
- *Pre-notification*
- *Training*
- *Competence of NEBs*



Interpretative Guidelines on Rail Passenger Rights

Clarification:

1. Clear Information about travel, tariffs and tickets (alternative formats for persons with disabilities)
2. PRM rights (no medical certificates needed)
3. Complaint handling, enforcement and cooperation

Recommendations:

1. Exemptions only as long as needed to phase in full application and for certain specific services
2. Broad offer of tickets via different sales channels
3. PRM rights: disability awareness measures and adequate training for service staff

Recent and planned developments

- Ongoing **revision of the Air passenger Rights Regulation** (*COM(2013) 130 final*) which strengthens provisions concerning PRM (in the field of assistance and mobility equipment)
- Possible revision of **rail** PRR (e.g. removal of exemptions, introduction of disability awareness training obligations, accessibility obligations) and
- Reflections on a possible new proposal concerning passenger rights in **multimodal** transport
- Application Reports on waterborne and bus & coach Regulations



Your Passenger Rights:
europa.eu/youreurope/citizens/travel/passenger-rights

Europe Direct: 00 800 6 7 8 9 10 11

European Consumer Centre:
ec.europa.eu/consumers/ecc



**Rechtliche Handlungsfähigkeit:
die Herausforderung der
Unterstützung bewältigen –
zwischen Unabhängigkeit
und Schutz**

Camille Latimier

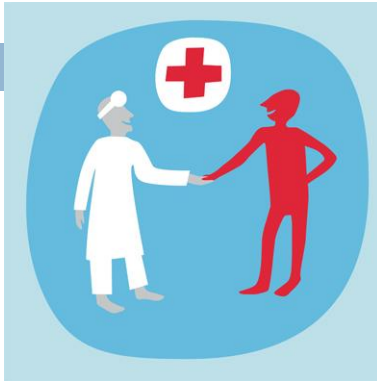
Trier, 23. Mai 2016

Einleitung

Entscheidungsfindung

- Rationale Entscheidungen?
- Externe Einflüsse: Kultur, Präferenzen und soziale Beziehungen
- Bedarf an fachkundiger Beratung
- Entscheidungen entsprechen möglicherweise nicht unserem „Wohl“
- Das Recht, Fehler zu machen, falsche Entscheidungen zu treffen

Entscheidungsbereiche



Gesundheit



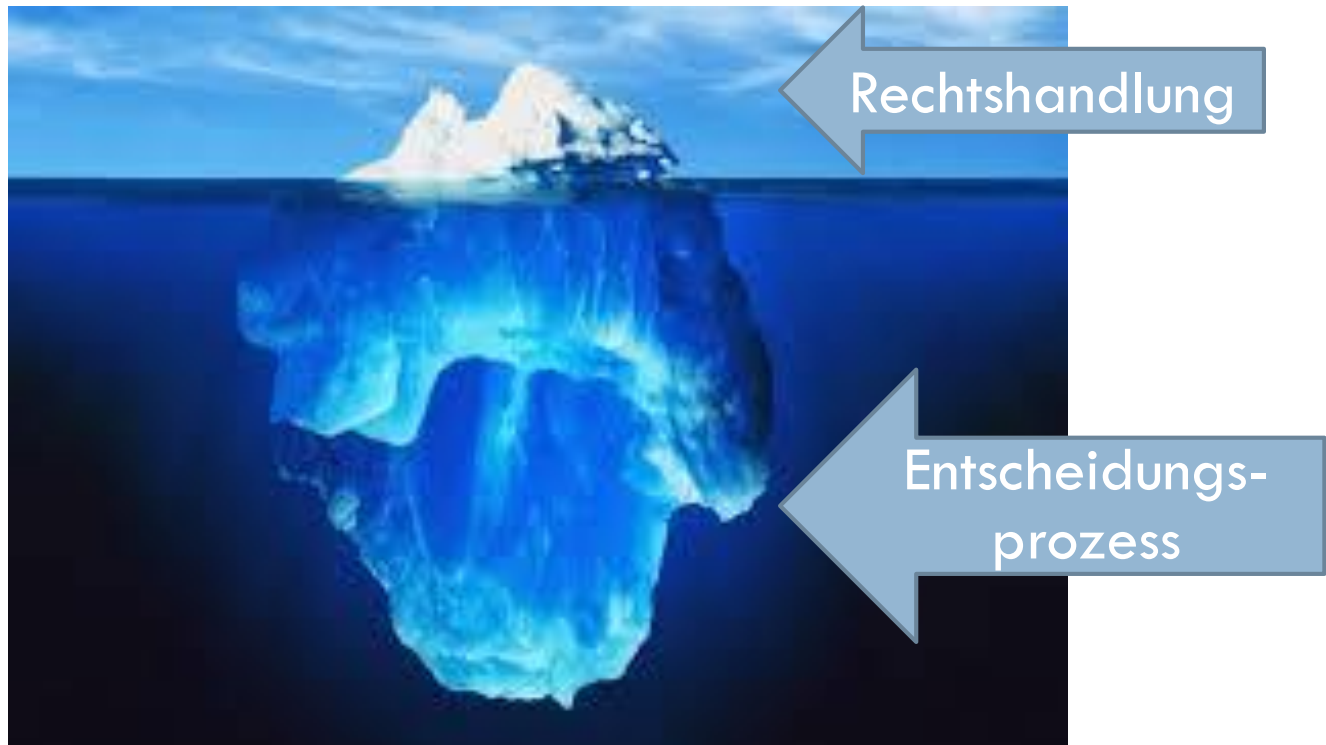
Geld, Vermögen



Persönliches Leben – wo und mit wem man lebt, welche Unterstützung, Arbeit, Privatleben, Familie



Entscheidungsfindung



Mit welchen Hindernissen sind behinderte Menschen konfrontiert?

- Rechtliche Handlungsunfähigkeit, Vormundschaft, Pflegschaft und andere Maßnahmen der ersetzenden Entscheidungsfindung
 - ▣ Etwa der Hälfte der Befragten mit geistiger Behinderung war die rechtliche Handlungsfähigkeit ganz oder teilweise entzogen worden, und sie waren unter unterschiedliche Formen der Vormundschaft gestellt worden.
 - ▣ Vormünder kümmern sich in der Regel um finanzielle Angelegenheiten, aber es kam vor, dass sie auch andere Aspekte des Lebens der Betroffenen kontrollierten.
 - ▣ Vormünder entscheiden auch, wo die betreffende Person lebt (mit oder ohne deren Zustimmung: Dies kann zur Entziehung der Freiheit führen.

Wahlfreiheit und Selbstbestimmung: das Recht auf unabhängige Lebensführung, Erfahrungen von Menschen mit geistiger Behinderung und Menschen mit psychischen Gesundheitsproblemen in neun EU-Mitgliedstaaten, Agentur der Europäischen Union für Grundrechte, 2012

Mit welchen Hindernissen sind behinderte Menschen konfrontiert?

- Zugang zur Justiz
 - Unter Vormundschaft stehende Menschen haben Schwierigkeiten bei der Durchsetzung ihrer Rechte
 - Fehlende Unterstützung: Betreuer oder Familienangehörige zeigen in der Regel weniger Bereitschaft, ihnen bei einer Beschwerde zu helfen.
 - Angst vor Vergeltung
 - Informationsdefizit: wie und bei wem eine Beschwerde einzulegen ist

Artikel 12 des Übereinkommens über die Rechte von Menschen mit Behinderungen

Gleiche Anerkennung vor dem Recht

– Artikel 12

1. Menschen mit Behinderungen haben das Recht, überall als Rechtssubjekt anerkannt zu werden.
2. Menschen mit Behinderungen genießen in allen Lebensbereichen gleichberechtigt mit anderen **rechtliche Handlungsfähigkeit**.
3. Sie haben Zugang zu der Unterstützung, die sie bei der Ausübung ihrer rechtlichen Handlungsfähigkeit **gegebenenfalls** benötigen.
4. Es müssen geeignete und wirksame Sicherungen vorgesehen werden, um Missbräuche zu verhindern.

Artikel 12 – Fortsetzung

Abs. 4 – Sicherungen gegen Missbräuche:

- ▣ Achtung der **Rechte, des Willens und der Präferenzen der betreffenden Person**
- ▣ Ohne Interessenkonflikte und missbräuchliche Einflussnahme
- ▣ Die Maßnahmen sind verhältnismäßig und auf die Umstände der Person zugeschnitten
- ▣ Von möglichst kurzer Dauer
- ▣ Sie unterliegen einer regelmäßigen, unabhängigen und unparteiischen Überprüfung.

Artikel 12 – Fortsetzung

Abs. 5 – Menschen mit Behinderungen haben das Recht, Eigentum zu besitzen oder zu erben, ihre finanziellen Angelegenheiten selbst zu regeln und gleichen Zugang zu Bankdarlehen, Hypotheken und anderen Finanzkrediten zu haben

Die Konsequenzen von Artikel 12

- Anerkennung der universellen rechtlichen Handlungsfähigkeit für alle Menschen ohne Diskriminierung aufgrund von Behinderung
- Das Übereinkommen ermächtigt nicht zu Vormundschaft, Pflegschaft oder anderen Formen der ersetzenden Entscheidungsfindung oder zum automatischen Verlust von Rechten
- Es werden neue Formen der Unterstützung (formelle und informelle) und Sicherungen vorgeschrieben
- **Die Anerkennung der Rechtspersönlichkeit ist eine Grundvoraussetzung für die Ausübung der anderen Rechte nach dem Übereinkommen.**

Allgemeine Bemerkung Nr. 1

Erkenntnisse des Ausschusses

Hintergrund

- Analyse der aus Artikel 12 resultierenden Verpflichtungen
- Die „genaue Reichweite der Verpflichtungen nach Artikel 12 des Übereinkommens [wird] generell missverstanden“
- Menschenrechtsbasiertes Modell von Behinderung

Daher die Allgemeine Bemerkung Nr. 1 zu Artikel 12

Rechtliche Handlungsfähigkeit versus geistige Fähigkeit

- Rechtliche Handlungsfähigkeit ist sowohl die Fähigkeit, Inhaber von Rechten und Pflichten zu sein (Rechtsfähigkeit) als auch diese Rechte und Pflichten auszuüben (Handlungsfähigkeit im Recht).
 - ▣ Rechtsverbindliche Regelungen mit anderen zu treffen: persönliche Angelegenheiten, Gesundheitsversorgung, Eigentum, Finanzen, Finanzkredite (siehe Art. 12 Abs. 5)
- Zu unterscheiden von der geistigen Fähigkeit:
 - ▣ Fähigkeit einer Person, Entscheidungen zu treffen; diese Fähigkeit ist naturgemäß von Person zu Person verschieden und kann auch beim einzelnen Menschen variieren, abhängig von vielen Faktoren, (umweltbedingte und soziale Faktoren).

Unterstützung

- „Unterstützung“ ist ein weit gefasster Begriff, der **sowohl informelle als auch formelle Arrangements** zur Unterstützung in unterschiedlicher Art und Intensität umfasst. (Randnr. 17)
- **Die Art und Intensität der anzubietenden Unterstützung** kann sich aufgrund der Vielfalt von Menschen mit Behinderungen von Person zu Person **erheblich unterscheiden**. (Randnr. 18)
- Manche Menschen wollen ihr Recht auf Unterstützung möglicherweise nicht wahrnehmen. (Randnr. 19)

Ausschuss für die Rechte von Menschen mit Behinderungen,
Allgemeine Bemerkung Nr. 1 zu Artikel 12

Formen der Unterstützung

- *eine oder mehrere Vertrauenspersonen;*
- *Peer-Support;*
- *Interessenvertretung (einschließlich Unterstützung bei der Selbstvertretung);*
- *Kommunikationsassistenz;*
- *nicht-konventionelle Kommunikationsmethoden;*
- *Vorsorgeverfahren;*
- *Maßnahmen in Bezug auf universelles Design und Zugänglichkeit (leicht lesbare und verständliche Informationen).*

Wille und Präferenzen

- Der Grundsatz des „Wohles“ ist keine Sicherung, die in Bezug auf Erwachsene mit Artikel 12 im Einklang steht.
- Das **Paradigma „Wille und Präferenzen“** muss an die Stelle des Paradigmas „Wohl“ treten, damit sichergestellt ist, dass Menschen mit Behinderungen in den gleichberechtigten Genuss des Rechts auf rechtliche Handlungsfähigkeit kommen.

*Ausschuss für die Rechte von Menschen mit Behinderungen,
Allgemeine Bemerkung Nr. 1 zu Artikel 12 (Randnr. 21)*

Paradigmenwechsel

- Das Übereinkommen wird schrittweise umgesetzt, **was jedoch im Falle der Bestimmungen zur Nichtdiskriminierung und zur rechtlichen Handlungsfähigkeit nicht gilt.**
- *„Die Entwicklung von Systemen der unterstützten Entscheidungsfindung bei gleichzeitiger Beibehaltung von Regelungen zur ersetzenden Entscheidungsfindung reicht nicht aus, um mit Artikel 12 in Einklang zu sein.“*

Ausschuss für die Rechte von Menschen mit Behinderungen,
Allgemeine Bemerkung Nr. 1 zu Artikel 12 (Randnr. 28)

Die Herausforderung

Regelung zur ersetzenden Entscheidungsfindung	System der unterstützten Entscheidungsfindung
Medizinische Diagnose	Individuelle Beurteilung des Unterstützungsbedarfs
Eine Reaktion – ein geeignetes Modell mit mehreren Varianten	Eine oder mehrere Arten von Unterstützung, die miteinander kombiniert werden könnten
Keine Unterscheidung zwischen den Unterstützungsbereichen	Ermittlung der Bereiche, in denen Unterstützung benötigt wird, sowie der richtigen Instrumente
Keine sachgerechte Überprüfung; formelhafte Beurteilung	Individuelle Evaluierung, Planung und (erneute) Beurteilung (Bedarf ändert sich)
Ein „einfaches“ Modell – eine einheitliche Reaktion	Ein komplexes Modell mit diversen Reaktionen und Unterstützungsmodellen

Die Auswirkungen

- **Rechtliche, politische, finanzielle, soziale Auswirkungen:**
 - Wo verläuft die Grenze zu der von Sozialdiensten geleisteten Unterstützung? Auswirkungen im Zusammenhang mit einer älter werdenden Bevölkerung
 - Welche Rolle spielt die Justiz im Hinblick auf die Beurteilung des Bedarfs? Mit wem kann zusammengearbeitet werden?
 - Wie ist mit Vorurteilen in der Gesellschaft und Einstellungen gegenüber Menschen mit einer Behinderung umzugehen?
 - Wie kann die Flexibilität in der alltäglichen Entscheidungsfindung gewahrt werden?
 - Wie kann kontrolliert werden, dass die betreffende Person gut unterstützt wurde?
 - Versicherung für Unterstützungspersonen und Verantwortung
 - Kosten?

Die Grundsätze

Betrachtung der unterstützten
Entscheidungsfindung in der Praxis

*Ausschuss für die Rechte von Menschen mit Behinderungen,
Allgemeine Bemerkung Nr. 1 zu Artikel 12 (Randnr. 29)*

Die Grundprinzipien (a)

- Unterstützte Entscheidungsfindung muss **allen offenstehen**. Der Umfang des Unterstützungsbedarfs (insbesondere wenn dieser hoch ist) sollte kein Hindernis sein, Unterstützung bei der Entscheidungsfindung zu bekommen;

Die Grundprinzipien (b)

- alle Formen der Unterstützung bei der Ausübung der rechtlichen Handlungsfähigkeit (einschließlich intensiverer Formen der Unterstützung) müssen **auf dem Willen und den Präferenzen der betroffenen Person** beruhen und nicht auf dem, was für ihr objektives Wohl erachtet wird;

Ein integratives Konzept

- Um ein integratives Konzept für die rechtliche Handlungsfähigkeit entwickeln zu können, muss überdacht werden, „wer“ sie ausübt und „wie“ dies geschieht
- Wir müssen über andere Kriterien der Persönlichkeit nachdenken
 - ▣ Jemand, der anderen gegenüber eine Absicht und einen „Willen“ zum Ausdruck bringt
 - ▣ Jemand der im Zeitablauf über eine „persönliche Identität“ verfügt – dessen Geschichte erzählt werden kann

Ein integratives Konzept

- Alle Individuen haben einen Willen – der von dem Individuum zum Ausdruck gebracht... oder von anderen (Vertrauenspersonen) gedeutet und beschrieben werden kann
- Der Wille oder die Absichten einer Person bilden die Grundlage einer kompetenten Entscheidungsfindung...
 - ▣ Menschen sind nicht unfähig oder ungeeignet – die Entscheidungsprozesse sind es

Praxis

- Jeder Mensch besitzt volle rechtliche Handlungsfähigkeit ohne Diskriminierung aufgrund von Behinderung.
- Die Gesetzgebung sollte eine Vermutung der Entscheidungsfähigkeit vorsehen.
~~Behinderung – Handlungsunfähigkeit~~
- Art. 5 BRK verbietet jede Diskriminierung aufgrund von Behinderung.
- Rechtsvorschriften sollten daher behinderungsneutral sein und so geändert werden, dass sie eine **Vermutung der Entscheidungsfähigkeit** enthalten.

Praxis

- Praxis in Fällen von Personen mit einer oder mehreren Behinderungen, ohne verbale Kommunikation
 - ▣ Aufzeichnungen über die Kommunikationsmethoden und -formen der betreffenden Person sowie über ihre Gewohnheiten
 - ▣ Nutzung ihrer persönlichen Identität und Geschichte bei der Ermittlung des Unterstützungsbedarfs, nicht der medizinischen oder psychologischen Begutachtung
 - ▣ Hinzuziehung von Zeugen, die über die Vertrauensverhältnisse der Person (Familie, Freunde usw.) sprechen können

Die Grundprinzipien (c)

- der **Kommunikationsmodus** einer Person darf kein Hindernis sein, Unterstützung bei der Entscheidungsfindung zu bekommen, selbst wenn diese Kommunikation nicht-konventionell ist oder von nur wenigen Menschen verstanden wird;

Die Grundlage

- Vorhandensein von Kommunikations- und alternativen Kommunikationsmitteln, um die Inklusion von Menschen mit schweren Behinderungen oder komplexen Erfordernissen zu gewährleisten.
- Das Kommunikationssystem ist von entscheidender Bedeutung, wenn es um unterstützte Entscheidungsfindung gehen soll.



Praxis – Beispiel British Columbia

- Die Anforderungen für die Beurteilung der Unfähigkeit, eine Vertretungsvereinbarung abzuschließen, sind sehr gering. Sie basiert auf Willen/Gefühlen/Vertrauen:
 - dass der Erwachsene den Wunsch nach einem Vertreter ausdrücken kann;
 - dass der Erwachsene Vorlieben und Entscheidungen aufzeigen und Gefühle von Zustimmung oder Ablehnung ausdrücken kann;
 - dass zwischen dem Erwachsenen und dem Vertreter eine auf Vertrauen basierende Beziehung besteht.

Die Grundprinzipien (d)

- die rechtliche Anerkennung der Unterstützungsperson(en), die von der betroffenen Person offiziell ausgewählt wurde(n), muss möglich und zugänglich sein, und der Staat hat eine Verpflichtung, die Schaffung von Unterstützungsmöglichkeiten zu erleichtern, insbesondere für **Menschen, die isoliert sind und möglicherweise keinen Zugang zu den in einer Gemeinschaft allgemein vorhandenen Unterstützungsmöglichkeiten haben.** Dies muss ein **Verfahren einschließen, das es Dritten ermöglicht, die Identität einer Unterstützungsperson nachzuprüfen, ebenso wie Verfahren, wodurch Dritte die Rechtshandlung einer Unterstützungsperson anfechten können,** wenn sie meinen, dass die Unterstützungsperson nicht nach dem Willen und den Präferenzen des Betroffenen gehandelt hat;

Praxis – „Unterstützernetze“

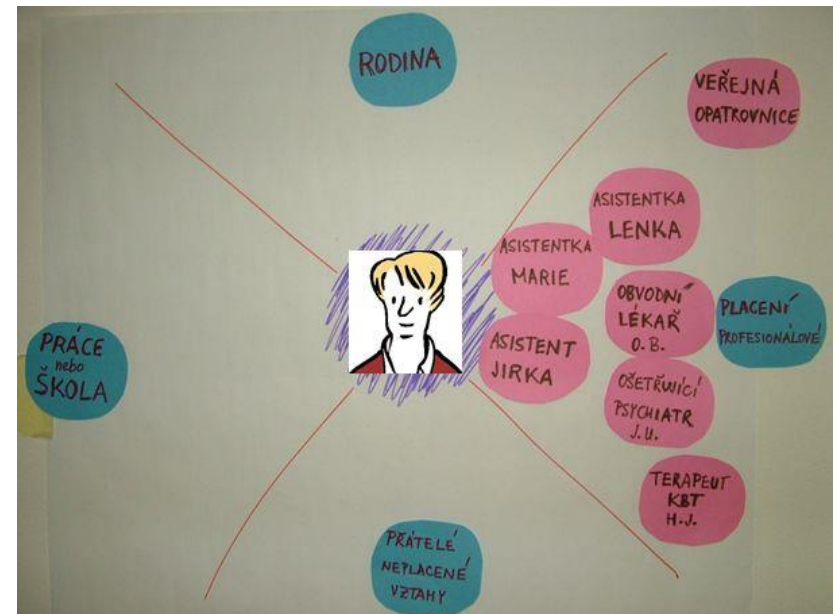
- Circles Network (UK) und PLAN in Kanada schaffen Beziehungen und ein soziales Gefüge für isolierte Menschen oder Menschen mit einer geringen Zahl von Beziehungen.
- Die Unterstützung durch nur eine einzige Person kann zu Abhängigkeit, Kontrolle, Missbrauch und einer einseitigen Wahrnehmung des Willens der betreffenden Person führen.
- Eine aus Peers, Freunden, Familienangehörigen, Nachbarn usw. bestehende Gruppe kann der betreffenden Person wirksamere und zuverlässigere Unterstützung gewähren.
- Unterschiedliche und langfristige, vertrauensvolle Beziehungen können das Leben der betreffenden Personen bereichern.

Die Rolle des Unterstützerkreises

Ein ausgewogener Kreis – Schutz



Ein unausgewogener Kreis – keine Kontrolle



Sicherungen und Schutz vor Missbrauch

- NIDUS, British Columbia
- Die Rolle einer (per Gesetz geschaffenen) nationalen Einrichtung:
 - ▣ Informationen zu unterstützter Entscheidungsfindung und angemessenen Vorkehrungen erteilen und diesbezüglich Unterstützung gewähren
 - ▣ Umfassende Aufzeichnungen über alle vorhandenen Unterstützungspersonen, Ansprechpartner und Überwacher führen und aktualisieren
 - ▣ Auf Anliegen und Beschwerden von Betroffenen, Dritten, Unterstützungspersonen und sich angesprochen fühlenden Bürgern eingehen – Mediation?
 - ▣ Und die Gerichte entlasten?

Die Grundprinzipien (e)

- um die Anforderung von Artikel 12 Absatz 3 zu erfüllen, dass alle Vertragsstaaten Maßnahmen ergreifen müssen, um „Zugang“ zu der benötigten Unterstützung „zu verschaffen“, müssen die Vertragsstaaten sicherstellen, dass Menschen mit Behinderungen Unterstützung zu erschwinglichen Kosten beziehungsweise kostenlos zur Verfügung steht und dass fehlende finanzielle Mittel kein Hindernis für den Zugang zu Unterstützung bei der Ausübung der rechtlichen Handlungsfähigkeit darstellen;

Die Grundprinzipien (f)

- Unterstützung bei der Entscheidungsfindung **darf nicht als Rechtfertigung für die Einschränkung anderer grundlegender Rechte** von Menschen mit Behinderungen, insbesondere des Wahlrechts, des Rechts eine Ehe zu schließen (beziehungsweise eine eingetragene Lebenspartnerschaft einzugehen) und eine Familie zu gründen, der reproduktiven Rechte, der elterlichen Rechte, des Rechts auf Zustimmung zu intimen Beziehungen und medizinischer Behandlung sowie des Rechts auf Freiheit benutzt werden;

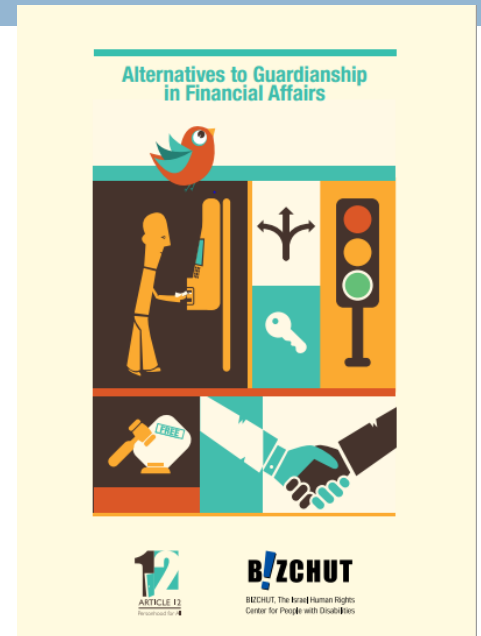
Unterstützungsoptionen

- Individuelle und flexible Maßnahmen: eine spezifische Reaktion für jeden Einzelnen
- Die unterstützte Entscheidungsfindung muss in flexibler Weise geregelt werden:
 - ▣ Eine oder mehrere Aufgaben: alltägliche finanzielle Angelegenheiten, persönliche Angelegenheiten, Gesundheit, Unterbringung, rechtliche Vertretung
 - ▣ Eine oder mehrere Personen kann/können als Unterstützungsperson(en) mit unterschiedlichen Aufgaben benannt werden.

Finanzen und Eigentum

- Vermögen, Grundbesitz, Finanzen und Verträge:
 - ▣ eine sensible Frage
 - ▣ Schutz vor irreversiblen Schäden (Recht, Fehler zu machen)

- Welche Vorkehrungen und welche Unterstützung?
 - ▣ Zugang zu Bankkonten
 - ▣ Vermögensverwaltung durch eine Vertrauensperson im Namen des Begünstigten (Treuhandfonds)



Die Grundprinzipien (g)

- die betroffene Person muss das Recht haben, **Unterstützung abzulehnen und das Unterstützungsverhältnis jederzeit zu beenden oder zu ändern;**

Selbsthilfe und Unabhängigkeit

- Förderung der Emanzipation, des selbstverantwortlichen Handelns und der Unabhängigkeit von Menschen mit Behinderung
- Arbeit mit Familien und Fachleuten
- Selbsthilfe vom Kindesalter an ist wichtig
- Lernen, Entscheidungen zu treffen



Die Grundprinzipien (h)

- für alle Prozesse in Verbindung mit der rechtlichen Handlungsfähigkeit und der Unterstützung bei ihrer Ausübung müssen **Sicherungen** geschaffen werden. Es muss Ziel dieser Sicherungen sein, zu gewährleisten, dass **der Wille und die Präferenzen** der betreffenden Person geachtet werden;

Welche Sicherungen?

1. Nationale Einrichtung/nationales Register
2. Gericht – Zuständigkeiten
3. Zugang zu Rechtsberatung
4. Zugang zu Rechtsanwälten/Vertretern:
 1. Beratung der Betroffenen über ihre Rechte im Bereich der Entscheidungsfindung
 2. Information der Betroffenen im Verlauf von Gerichtsverfahren
 3. Unterstützung der Betroffenen beim Treffen und Kommunizieren von Entscheidungen
 4. Erläuterung der Art und der Auswirkungen des Verfahrens
5. Rechtsfähigkeit für Unterstützungspersonen
6. Ein Überwacher

Beispiel British Columbia

- Vertretungsvereinbarungen müssen vor Zeugen geschlossen werden: Wird die Vereinbarung nicht mit einem Rechtsanwalt geschlossen, sind zwei Zeugen erforderlich.
- Es wird ein **Überwacher** benannt – für laufende finanzielle Angelegenheiten. Der Überwacher hat eine spezifische Rolle. Der Überwacher hat die Aufgabe, dafür Sorge zu tragen, dass der Vertreter seinen Pflichten nachkommt. Überwacher können bei Bedarf auch Unterstützung gewähren und zur Lösung von Problemen beitragen, und laut Gesetz kann ihnen der Kontakt mit dem betreffenden Erwachsenen nicht versagt werden.

Die Grundprinzipien (i)

- die Bereitstellung von Unterstützung bei der Ausübung der rechtlichen Handlungsfähigkeit sollte nicht von der Beurteilung der geistigen Fähigkeit abhängen; für die Feststellung des Unterstützungsbedarfs sind **neue, nichtdiskriminierende Indikatoren** erforderlich.

Diskussion

Ihre Fragen!

Vielen Dank für Ihre Aufmerksamkeit!

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**La capacité juridique:
comment relever le défi de
l'accompagnement entre
autonomie et protection**

Camille Latimier

Trèves, le 23 mai 2016

Introduction

Prendre des décisions

- Des décisions rationnelles?
- Les influences extérieures: la culture, les préférences, les relations sociales
- Besoin de conseils d'expertise
- Les décisions peuvent ne pas être dans notre «intérêt supérieur»
- Droit de faire des erreurs, de prendre de mauvaises décisions

Sphères de décisions



Santé



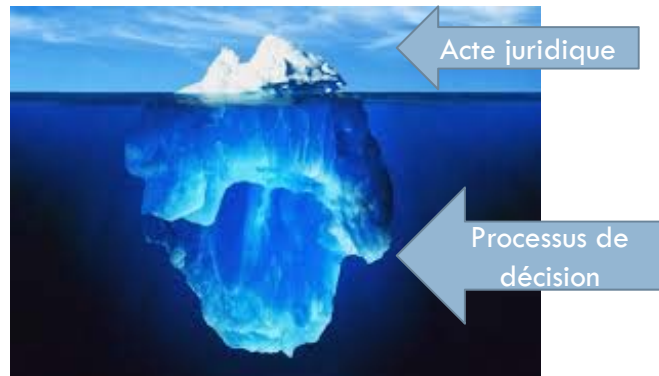
Argent, biens



Vie personnelle— où et avec qui vivre, quels accompagnements, le travail, la vie intime, la famille



Prendre des décisions



Quels sont les obstacles auxquels les personnes handicapées font face?

- Incapacité juridique, tutelle, curatelle et autres mesures de prise de décisions substitutive
 - ▣ Environ la moitié des personnes avec un handicap intellectuel interrogées avaient été entièrement ou partiellement privées de leur capacité juridique et placées sous différentes formes de tutelle
 - ▣ Les tuteurs prennent généralement en charge les questions financières, mais il arrivait qu'ils contrôlent également d'autres aspects de la vie des intéressés
 - ▣ Les tuteurs décident aussi du lieu de vie de la personne (avec ou sans son consentement): ce qui parfois engendre une privation de liberté

Choix et contrôle : le droit à une vie autonome, expériences de personnes handicapées intellectuelles et de personnes souffrant de troubles mentaux dans neuf États membres de l'Union européenne, Fundamental Rights Agency, 2012

Quels sont les obstacles auxquels les personnes handicapées font face?

- Accès à la justice
 - ▣ Les personnes sous tutelles ont du mal à faire valoir leurs droits
 - ▣ Manque de soutien: auxiliaires de vie ou membres de la famille sont généralement moins disposés à les assister pour porter plainte officiellement.
 - ▣ Peur des représailles
 - ▣ Manque de connaissances : comment et auprès de qui porter plainte

L'article 12 de la Convention relative
aux droits des personnes handicapées

Reconnaissance de la personnalité juridique -Article 12

1. Les personnes handicapées ont droit à la reconnaissance en tous lieux de leur personnalité juridique.
2. les personnes handicapées jouissent **de la capacité juridique** dans tous les domaines, sur la base de l'égalité avec les autres.
3. Elles ont accès à un accompagnement approprié dont elles **peuvent** avoir besoin pour exercer leur capacité juridique.
4. Elles doivent être assorties de garanties appropriées et effectives pour prévenir les abus

Article 12 – suite

§ 4 Garanties contre les abus:

- ▣ Le respect des droits, **de la volonté et des préférences de la personne concernée**
- ▣ Exempt de tout conflit d'intérêt et d'abus d'influence
- ▣ Mesures proportionnées et adaptées à la situation de la personne concernée
- ▣ Pour la période la plus brève possible
- ▣ Soumises à un contrôle périodique indépendant et impartial.

Article 12 - suite

§5 Les personnes handicapées ont le droit de posséder des biens ou d'en hériter, de contrôler leurs finances et d'avoir accès aux mêmes conditions que les autres personnes aux prêts bancaires, hypothèques et autres formes de crédit financier

Les conséquences de l'article 12

- La reconnaissance de la capacité juridique universelle pour toutes les personnes sans discrimination fondée sur le handicap
- La Convention n'autorise ni tutelle ni curatelle ni aucune forme de prise de décisions substitutive ou perte automatique des droits
- De nouvelles formes d'accompagnement (formel et informel) et des garanties sont nécessaires
- **La reconnaissance de la personnalité juridique est une condition préalable pour la réalisation des autres droits contenus dans la Convention.**

Observation générale n°1

Ou les éclairages apportés par le Comité

Le contexte

- Analyse des obligations découlant de l'article 12
- « existence d'un malentendu général en ce qui concerne la portée exact des obligations »
découlant de l'article 12
- Conception du handicap axée sur les droits de l'homme

D'où l'observation générale n°1 sur l'article 12

Capacité juridique versus capacité mentale

- La capacité juridique est la capacité d'avoir des droits et des obligations (statut juridique) et d'exercer ces droits et d'exécuter ces obligations (capacité d'agir en droit).
 - ▣ prendre des dispositions juridiquement contraignantes avec les autres: affaires personnelles, soins de santé, biens, finances, crédit financier (voire Art.12§5)
- A différencier de la capacité mentale:
 - ▣ la capacité d'une personne de prendre des décisions varie naturellement d'une personne à l'autre et peut également varier dans le cas d'une même personne en fonction de nombreux facteurs (sociaux, environnement).

Les accompagnements

- Le terme «accompagnement» a un caractère générique et englobe **des mesures tant formelles qu'informelles**, de nature et de degré divers. (§17)
- **La nature et le degré de l'accompagnement** à apporter **varient considérablement** d'une personne à l'autre, en raison de la diversité des personnes handicapées. (§18)
- Certaines personnes peuvent ne pas souhaiter exercer le droit à un accompagnement (§19)

Comité DPH, Observation générale n°1 sur l'article 12

Les formes d'accompagnement

- Une ou plusieurs personnes de confiance;
- Le soutien par les pairs,
- La défense de leurs intérêts (y compris l'auto-représentation),
- L'aide à la communication
- Méthodes non conventionnelles de communication
- Méthodes de planification
- mesures relatives à la conception universelle et à l'accessibilité (information facile à lire et à comprendre)

Volonté et préférences

- Le principe de l'«intérêt supérieur» n'est pas une garantie conforme à l'article 12 s'agissant d'adultes.
- **Le paradigme «de la volonté et des préférences»** doit remplacer le paradigme de «l'intérêt supérieur» pour que les personnes handicapées jouissent de leur droit à la capacité juridique à égalité avec les autres.

Comité DPH, Observation générale n°1 sur l'article 12 § 21

Changement de paradigme

- La mise en œuvre de la convention se fait progressivement mais **cela ne s'applique pas dans le cas des dispositions sur la non-discrimination et sur la capacité juridique.**
- « *Élaborer des régimes de prise de décisions assistée tout en maintenant en parallèle des régimes de prise de décisions substitutive n'est pas suffisant pour se conformer à l'article 12 de la Convention.* »

Comité DPH, Observation générale n°1 sur l'article 12 § 28

Le défi

Système de prise de décisions substitutive	Système de prise de décisions assistée
Diagnostic médical	Évaluation individuelle des besoins d'accompagnement
Une réponse – un modèle décliné avec quelques variations	Un ou plusieurs accompagnement(s) qui peuvent se combiner
Pas de distinction entre les domaines d'accompagnement	Identification des domaines où un accompagnement est nécessaire et ses outils adéquats
Pas de critique appropriée; examen mécanique	Évaluation individuelle, planification, et (re-)examen (les besoins évoluent)
Un modèle « facile» - une réponse unique	Un modèle complexe où il existe un ensemble de réponses et de modèles d'accompagnement

Les enjeux

- **Juridiques, politiques, financiers, sociaux:**
 - ▣ Oú est la frontière avec les accompagnements fournis par les services sociaux ? Enjeux liés à une population vieillissante
 - ▣ Quel rôle pour la justice en terme d'évaluation des besoins ? Avec qui travailler ?
 - ▣ Comment faire face aux préjudices dans la société et à l'attitude par rapport aux personnes handicapées ?
 - ▣ Comment garder la flexibilité des décisions quotidiennes ?
 - ▣ Comment vérifier que la personne a été bien accompagnée ?
 - ▣ L'assurance pour les personnes de soutien et la responsabilité
 - ▣ Le coût ?

Les principes

Ou comment envisager la prise de décisions assistée en pratique

Comité DPH, Observation générale n°1 sur l'article 12 § 29

Les principes essentiels - a

- La prise de décisions assistée doit être **accessible à tous**. Le niveau d'accompagnement dont une personne a besoin, en particulier s'il est élevé, ne devrait pas être un obstacle à l'obtention d'un accompagnement dans la prise de décisions;

Les principes essentiels - b

- Toutes les formes d'accompagnement dans l'exercice de la capacité juridique, y compris les formes d'accompagnement plus soutenues, doivent être fondées **sur la volonté et les préférences de la personne**, et non sur ce qui est perçu comme répondant objectivement à son intérêt supérieur;

Un approche inclusive

- Pour développer une approche inclusive à la capacité juridique, nous devons repenser «qui » l'exerce et « comment »
- Il faut penser à d'autres critères de la personnalité
 - ▣ Quelqu'un qui exprime une intention et de la «volonté» à d'autres
 - ▣ Quelqu'un qui a une «identité personnelle» à travers le temps – dont l'histoire peut être racontée par quelqu'un

Une approche inclusive

- Tous les individus ont une volonté - qui peut être exprimée par l'individu ... ou interprétée et décrite par d'autres (personnes de confiance)
- La volonté ou les intentions d'une personne forment la base de la prise de décisions compétente ...
 - ▣ Les gens ne sont pas incompetents ou inaptes - les processus de prise de décisions le sont

Pratique

- Tout le monde a la pleine capacité juridique sans discrimination sur la base du handicap.
- La législation devrait prévoir une présomption de compétence. ~~Incapacité=invalidité~~
- Art. 5 CDPH interdit toute discrimination sur la base du handicap.
- La législation devrait donc être neutre par rapport au handicap et être modifiée pour inclure une **présomption de compétence**

Pratique

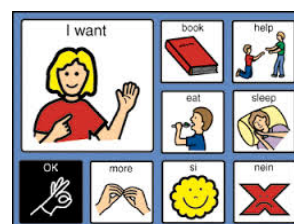
- Pratique avec des personnes handicapées ou polyhandicapées, n'ayant pas de communication verbale
 - Tenir un registre des méthodes et des formes de communication de la personne, ses habitudes
 - Utiliser l'identité et l'histoire personnelle pour déterminer les besoins de soutien pas de certificat médical ou psychologique
 - Utiliser des témoins qui peuvent parler des relations de confiance de la personne (famille, amis...)

Les principes essentiels - c

- Le **mode de communication** d'une personne ne doit pas être un obstacle à l'obtention d'une aide à la prise de décisions, même lorsque ce mode de communication n'est pas conventionnel ou est compris d'un très petit nombre de personnes;

La base

- La communication et les outils de communication alternatifs sont en place pour assurer l'inclusion des personnes atteintes de handicaps sévères ou ayant des besoins complexes.
- Le système de communication est clé pour pouvoir parler de prise de décisions assistée



Pratique – exemple de Colombie Britannique

- Le test d'incapacité pour entrer dans un Accord de représentation est très faible. Il est basé sur la volonté / les sentiments / la confiance:
 - Que l'adulte communique le désir d'avoir un représentant;
 - Que l'adulte démontre des choix et des préférences et peut exprimer des sentiments d'approbation ou de désapprobation des autres;
 - Que l'adulte a une relation avec le représentant qui est caractérisée par la confiance

Les principes essentiels - d

- La reconnaissance juridique de la ou des personne(s) de confiance officiellement choisie(s) par une personne doit être disponible et accessible, et les États sont tenus de faciliter la mise en place de l'accompagnement, notamment pour les **personnes qui sont isolées et n'ont pas naturellement accès à un soutien dans leur communauté**. Les mesures prises doivent prévoir un **mécanisme permettant à des tiers de vérifier l'identité des personnes de confiance, ainsi qu'un mécanisme permettant à des tiers de contester les actes accomplis par ces personnes** s'ils pensent qu'elles n'agissent pas conformément à la volonté et aux préférences de la personne concernée;

Pratique « circles of support »

- Circles Network, UK, ou PLAN au Canada créent des relations et un tissu social pour des personnes isolées ou ayant peu de relations.
 - ▣ Soutien par une seule personne peut conduire à la dépendance, de contrôle, d'abus et une perception unilatérale de la volonté d'un individu
 - ▣ Un groupe comprenant les pairs, les amis, les membres de la famille, les voisins, etc. peut fournir un soutien plus efficace et fiable à un individu.
 - ▣ Des relations variées, de confiance et de longue durée peuvent faire une différence dans la vie des individus.

Le rôle du cercle de soutien

Un cercle équilibré protection



Un cercle déséquilibré pas de contrôle



Garanties et protection contre les abus

- NIDUS, Colombie Britannique
- Le rôle d'une agence nationale (créée par la loi):
 - ▣ Fournir de l'information et de l'assistance en matière de prise de décision assistée et d'aménagements raisonnables
 - ▣ Maintenir et mettre à jour un registre complet de toutes les personnes de soutien, les facilitateurs et moniteurs existants
 - ▣ Entendre les préoccupations et les plaintes émanant de particuliers, de tiers, de personnes de soutien, de citoyens qui se sentent concernés – médiation?
 - ▣ Et désengorger les tribunaux?

Les principes essentiels - e

- Le paragraphe 3 de l'article 12 de la Convention les obligeant à prendre des mesures pour «donner accès» à l'accompagnement nécessaire, les États parties doivent faire le nécessaire pour que cet accompagnement soit proposé aux personnes handicapées à un prix symbolique ou gratuitement, et pour que le manque de ressources financières ne constitue pas un obstacle à l'accès à l'accompagnement dans l'exercice de la capacité juridique;

Les principes essentiels - f

- L'accompagnement dans la prise de décisions **ne doit pas être invoqué pour justifier la limitation d'autres droits fondamentaux** des personnes handicapées, notamment le droit de vote, le droit de se marier ou d'établir un partenariat civil et de fonder une famille, les droits en matière de procréation, les droits parentaux, le droit de consentir aux relations intimes et aux traitements médicaux, ainsi que le droit à la liberté;

Un accompagnement à la carte

- Mesures individuelles et flexibles: pour chaque personne, il y a une réponse spécifique
- La prise de décisions assistée doit être arrangée de manière flexible:
 - ▣ Une ou un groupe de tâches: affaires financières quotidiennes, les affaires personnelles, santé, logement, représentation juridique
 - ▣ Une ou plusieurs personnes peuvent être nommés en tant que personnes de soutien avec des tâches différentes.

Les finances et les biens

- Actifs, immobilier, finance et contrats:

- ▣ question sensible
- ▣ Protection contre les dommages irréversibles (droit de faire une erreur)



- Quels aménagements et accompagnements ?

- ▣ Accès aux comptes bancaires
- ▣ Administration des biens par une personne de confiance pour le compte d'un bénéficiaire (trust fund)

Les principes essentiels - g

- La personne doit avoir le droit de **refuser l'accompagnement et de mettre fin à la relation d'accompagnement ou de la modifier à tout moment;**

Auto-représentation et autonomie

- Favoriser l'émancipation, la responsabilisation et l'autonomie des personnes handicapées
- Travailler avec les familles et les professionnels
- L'auto-représentation dès le plus jeune âge est importante
- Apprendre à prendre des décisions



Les principes essentiels - h

- Des **garanties** doivent être mises en place pour toutes les procédures relatives à la capacité juridique et à l'accompagnement dans l'exercice de cette capacité. Le but de ces garanties est d'assurer que **la volonté et les préférences** de la personne sont respectées;

Quelles garanties ?

1. Agence nationale/registre
2. Tribunal – compétences
3. Accès au conseil juridique
4. Accès à des avocats / représentants:
 1. conseiller les gens sur leurs droits à la prise de décision
 2. fournir des informations aux personnes dans le cadre de procédures judiciaires
 3. aider les gens à faire et à communiquer leurs décisions
 4. expliquer la nature et les implications de la procédure
5. Un statut juridique pour les personnes de soutien
6. Un moniteur

Exemple de Colombie Britannique

- Les accords de représentation doivent se conclure devant témoins: si l'accord ne se fait pas avec un avocat, alors deux témoins sont nécessaires.
- Un **moniteur** est nommé - pour les affaires financières courantes. Le moniteur a un rôle particulier. Le moniteur est là pour veiller à ce que le représentant accomplisse ses fonctions. Le moniteur peut fournir également un soutien et aider à résoudre des problèmes si nécessaire, et la loi dit que nul ne peut l'empêcher d'avoir des contacts avec l'adulte en question.

Les principes essentiels - i

- La fourniture d'un accompagnement dans l'exercice de la capacité juridique ne devrait pas dépendre d'une évaluation de la capacité mentale; de **nouveaux indicateurs, non discriminatoires**, du besoin d'accompagnement sont nécessaires aux fins de la fourniture d'un accompagnement dans l'exercice de la capacité juridique.

Discussion

A vos questions!

Merci pour votre attention!

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Durchführung der UN-Behindertenrechtskonvention:
Überwachungsphase

Art. 33 Abs. 3 BRK: Einbeziehung von Behindertenorganisationen
und Zivilgesellschaft

An-Sofie Leenknecht, EDF-Menschenrechtsbeauftragte,
Europäische Rechtsakademie, Trier, 23. Mai 2016

ÜBERBLICK

- Einbeziehung von Behindertenorganisationen in die Durchführung der BRK (Art. 4 Abs. 3 und Art. 33 Abs. 1 BRK)
- Einbeziehung von Behindertenorganisationen in die nationale und internationale Überwachung der BRK (Art. 33 Abs. 3 BRK)
- Beispiel für den Überprüfungsprozess der EU und die Einbeziehung des EDF und seiner Mitglieder vor dem Ausschuss für die Rechte von Menschen mit Behinderungen

ALLGEMEINE GRUNDSÄTZE DER TEILHABE UND INKLUSION

- Teilhabe ist wichtig, um die besonderen Bedürfnisse richtig zu ermitteln und den Einzelnen zu stärken
- Die volle und wirksame Teilhabe an der Gesellschaft und die Einbeziehung in die Gesellschaft wird in dem Übereinkommen anerkannt als:
 - ein allgemeiner Grundsatz (Artikel 3)
 - eine allgemeine Verpflichtung (Artikel 4)
 - ein grundlegendes politisches Recht (Artikel 29 und 30)

„Nichts über uns ohne uns“

Artikel 4 Absatz 3...

- Stärkung von Konsultationsmechanismen im Zusammenhang mit Art. 4 Abs. 3
- Einbeziehung von Menschen mit Behinderungen und ihrer Vertretungsorganisationen, einschließlich von Frauen und Kindern, auf allen Ebenen von öffentlichen Entscheidungsprozessen
- Konsultationen mit den Vertretungsorganisationen von Menschen mit Behinderungen über die Entwicklung von Unterstützungsdiensten für Menschen mit Behinderungen bei der unabhängigen, selbstbestimmten Lebensführung
- Konsultationen mit Behindertenorganisationen über Schulungen zum Thema der Anerkennung der rechtlichen Handlungsfähigkeit und zu Mechanismen der unterstützten Entscheidungsfindung
- Konsultation von Kindern mit Behinderungen und deren Eltern zu ihrem Unterstützungsbedarf im Zusammenhang mit der Ausübung des Rechts auf Bildung
- Konsultationen bei der Ausarbeitung einer neuen Verfassung sowie von Rechtsvorschriften und Politiken
- Im jeweiligen Land stattfindende internationale Kooperationsprojekte

Übergreifender Grundsatz der verantwortungsbewussten Regierungsführung

- Staaten müssen einen Rechtsrahmen schaffen, der der unmittelbaren und mittelbaren Einbeziehung von Menschen mit Behinderungen in die Rechtssetzung und Politikgestaltung förderlich ist
- Änderung und Aufhebung von Rechtsvorschriften und politischen Strategien, die die Fähigkeit von Menschen mit Behinderungen und ihrer Vertretungsorganisationen zur Mitwirkung einschränken
- Vorherige Konsultation und Einbindung der Vertretungsorganisationen in allen Phasen öffentlicher Entscheidungsprozesse, auch vor der Verabschiedung neuer Rechtsvorschriften und politischer Strategien.
- Die Rechtsprechung des Ausschusses für die Rechte von Menschen mit Behinderungen fordert für die Durchführung der systematischen Konsultation formale Mechanismen und Protokolle auf allen Regierungsebenen (Beratungsorgane oder andere Formen)

Artikel 4 Absatz 3...

Der Ausschuss für die Rechte von Menschen mit Behinderungen empfiehlt, dass der Vertragsstaat:

„(a) eine Strategie für die umfassende und frühzeitige Einbeziehung der Organisationen von Menschen mit Behinderungen in alle für Menschen mit Behinderungen in allen Sektoren relevanten politischen Entscheidungsprozesse entwickelt, einführt und umsetzt, einschließlich der Umsetzung und Überwachung der nachhaltigen Entwicklungsziele;

(b) für die ausreichende finanzielle Unterstützung für den Aufbau von Kapazitäten und die autonome Einbeziehung dieser Organisationen in alle Entscheidungsprozesse sorgt.“

Abschließende Bemerkungen zu Litauen,
April 2016

EINBEZIEHUNG IN DIE ÜBERWACHUNG AUF NATIONALER EBENE

- **Gesetzgebung und Politik:** Errichtung einer unabhängigen Überwachungsstelle im Einklang mit den Pariser Grundsätzen
- **Einbeziehung von Behindertenorganisationen:**
 - Gewährleistung der vorrangigen, umfassenden Einbeziehung von Menschen mit Behinderungen und ihrer Vertretungsorganisationen in den Überwachungsprozess
 - Schaffung eines unabhängigen Überwachungsmechanismus mit permanenter Konsultation von Behindertenorganisationen
- **Mittelausstattung:** Ausstattung des unabhängigen Überwachungsmechanismus mit den nötigen Mitteln (im Einklang mit den Pariser Grundsätzen) für die Erfüllung seiner Aufgabe der wirksamen Überwachung der Durchführung der BRK.

Empfehlungen des Ausschusses für die Rechte von Menschen mit Behinderungen

„den Organisationen von Menschen mit Behinderungen und anderen Organisationen der Zivilgesellschaft **angemessene Mittel** bereitzustellen, damit diese in vollem Umfang und wirksam am nationalen Durchführungs- und Überwachungsprozess teilnehmen können“

Der Ausschuss äußerte Bedenken, dass es einer unabhängigen Überwachungsstelle an „Möglichkeiten für Outreach-Maßnahmen in ländlichen Gebieten fehlte. Zudem sieht der Ausschuss mit Sorge, dass Organisationen von Menschen mit Behinderungen und andere Organisationen der Zivilgesellschaft von der Regierung **keine ausreichende Unterstützung erhalten**, um sie zur Teilnahme an der nationalen Durchführung und Überwachung zu befähigen.“

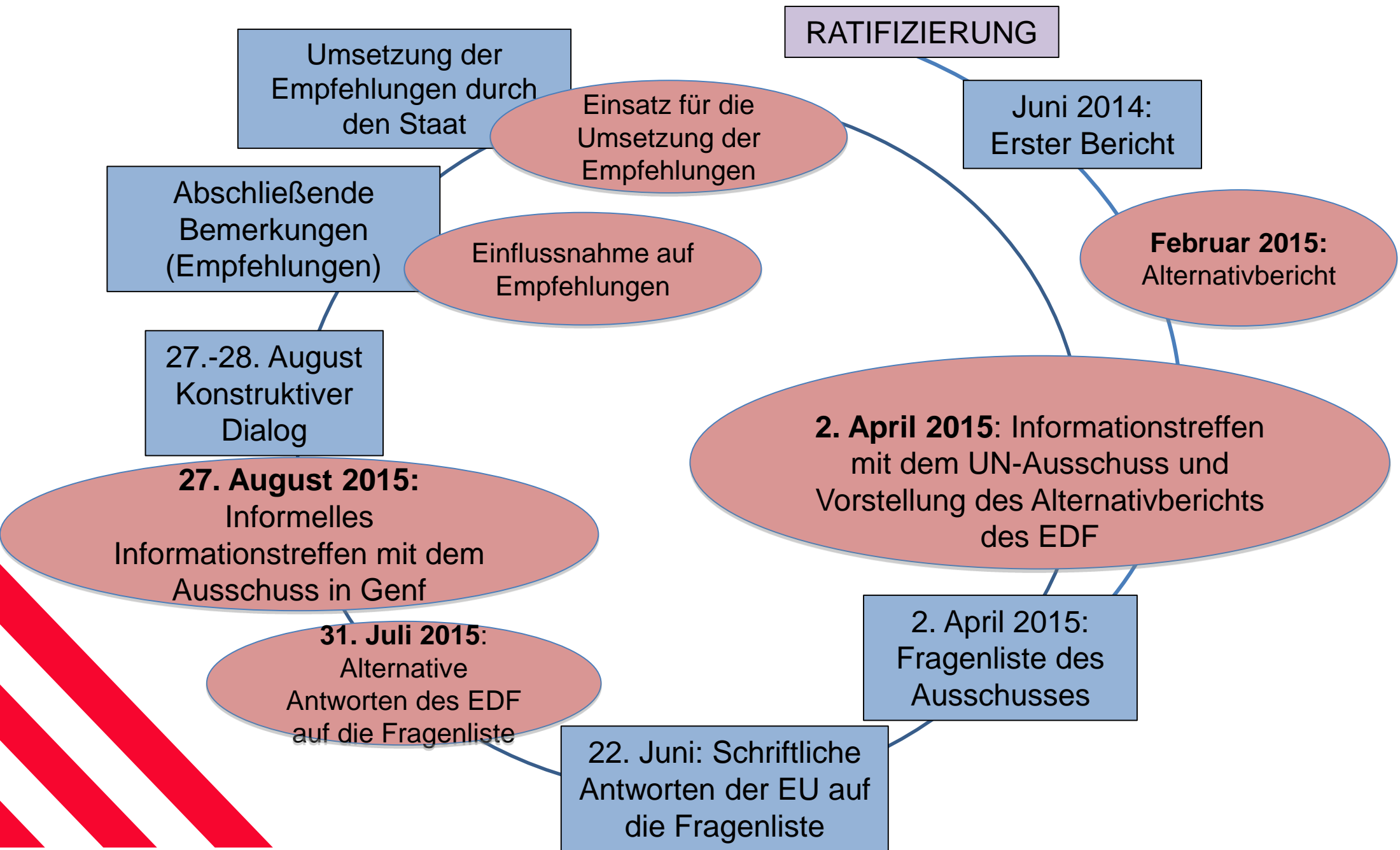
EINBEZIEHUNG IN DIE ÜBERWACHUNG AUF NATIONALER EBENE

- Die meisten Überwachungsstellen in der EU beziehen Behindertenorganisationen ein
- Beispiel:
 - In Italien und Slowenien sind ein Drittel der Mitglieder der Überwachungsstelle Vertreter von Behindertenorganisationen.
 - In der Slowakei sind die Hälfte der Mitglieder der Überwachungsstelle Vertreter von Behindertenorganisationen.
 - Im litauischen Rat für Behindertenfragen, dem einen Teil einer zweigliedrigen Überwachungsstelle, sind die Hälfte der Mitglieder des Rates Vertreter von Behindertenorganisationen.
 - In Dänemark sind Behindertenorganisationen im Vorstand des Dänischen Instituts für Menschenrechte sowie im Rat für Menschenrechte, der die Arbeit des Instituts erörtert, vertreten.
 - Spanien ist das einzige Beispiel, in dem eine Behindertenorganisation selbst die Überwachungsstelle darstellt.
 - Auf EU-Ebene ist das EDF Mitglied des Überwachungsrahmens (zusammen mit der Agentur für Grundrechte, dem Europäischen Bürgerbeauftragten und dem Europäischen Parlament).

Beispiel des Europäischen Behindertenforums und seiner Mitglieder

- Die EU reichte ihren ersten Bericht im Juni 2014 bei den Vereinten Nationen ein
- Der UN-Ausschuss für die Rechte von Menschen mit Behinderungen überprüfte die EU im April und August 2015
- Das EDF und seine Mitglieder verfassten einen Alternativbericht, Vorschläge für eine Fragenliste und alternative Antworten auf die Fragenliste
- Präsenz des EDF in Genf – 3 Begleitveranstaltungen im April und August 2015 zur Unterrichtung des Ausschusses über die Prioritäten des EDF
- Annahme der abschließenden Bemerkungen im September 2015
- Klar definierter Fahrplan für die Durchführung der BRK in den kommenden vier Jahren und Grundlage für die Arbeit des EDF und seiner Mitglieder im Bereich der Interessenvertretung auf EU- und nationaler Ebene

Chancen für Behindertenorganisationen: Pläne des EDF im Überprüfungsprozess der EU



ABSCHLIESSENDE BEMERKUNGEN DES AUSSCHUSSES FÜR DIE RECHTE VON MENSCHEN MIT BEHINDERUNGEN AN DIE EU

Artikel 4 Absatz 3 BRK

- Der Ausschuss ist besorgt angesichts des Fehlens eines übergreifenden, allgemeinen Rahmens für Konsultationen zwischen verschiedenen Organen in der Europäischen Union und Menschen mit Behinderungen, einschließlich von Frauen, Mädchen und Jungen mit Behinderungen, über die sie vertretenden Organisationen.
- Begründung eines strukturierten Dialogs für Menschen mit Behinderungen und ihre Vertretungsorganisationen in allen Entscheidungsprozessen der EU, mit einem unabhängigen Budget und ausreichender Mittelausstattung für die Konsultation mit und die Einbeziehung von Menschen mit Behinderungen.



Die Delegation der europäischen Behindertenbewegung in Genf



QUELLEN

Bericht der UN-Sonderberichterstatterin zu den Rechten von Menschen mit Behinderungen über die Einbeziehung in Entscheidungsprozesse

Alternativbericht des EDF

Bericht der EU und Fragenliste des UN-Ausschusses

Abschließende Bemerkungen des Ausschusses für die Rechte von Menschen mit Behinderungen an die EU

Bibliothek mit Positionspapieren des EDF auf www.edf-feph.org

VIELEN DANK FÜR IHRE AUFMERKSAMKEIT!

FRAGEN und ANMERKUNGEN?

Kontaktieren Sie mich gerne direkt unter
Ansofie.Leenknecht@edf-feph.org

EUROPÄISCHES BEHINDERTENFORUM

.....
An-Sofie Leenknecht, Europäisches
Behindertenforum



Implementing the UN CRPD: monitoring phase
Article 33 (3) CRPD: involvement of DPOs and civil society

An-Sofie Leenknecht, EDF Human Rights Officer,
European Academy of Law, Trier, 23 May 2016

OUTLINE

- DPOs' involvement in the implementation of the CRPD (articles 4,3 and 33, 1 CRPD)
- DPO's involvement in the national and international monitoring of the CRPD (article 33, 3 CRPD)
- Example of the EU review process and EDF and members involvement before the CRPD Committee

GENERAL PRINCIPLES ON PARTICIPATION AND INCLUSION

- Participation is important to correctly identify specific needs, and to empower the individual
- Full and effective participation and inclusion in society is recognized in the Convention as:
 - A general principle (article 3)
 - A general obligation (article 4)
 - A fundamental political right (articles 29 and 30)

'Nothing about us, without us'

Convention on the Rights of Persons
with Disabilities

PARTICIPATION IN DECISION MAKING

Article 4(3)...

- Strengthen consultation mechanisms re Article 4(3)
- Participation of persons with disabilities and their representative organisations including participation of women and children at all levels of public decision making
- Consult with organisations of persons with disabilities on developing support services for persons with disabilities to live independently in accordance with their own choice.
- Consult with DPOs on training on recognition of legal capacity and mechanisms of supported decision-making
- Consulting children with disabilities and their parents on support needs to enjoy right to education
- Consultation in drafting new Constitution and legislation, policy
- International cooperation projects taking place in their country

PARTICIPATION IN DECISION MAKING

Cross cutting principle of good governance

- States must adopt a legal framework conducive to the direct and indirect participation of persons with disabilities in law and policymaking
- Amending and repealing law and policy that limit the ability of persons with disabilities and their representative organisations to participate
- Prior consultation and engagement of representative organisations at all stages of public decision making, including before the adoption of new laws and policy.
- CRPD Committee jurisprudence asks for formal mechanisms and protocols, at all levels of the government to conduct the systematic consultation (consultative bodies or other forms)

PARTICIPATION IN DECISION MAKING

Article 4(3)...

The CRPD Committee recommends that the State party:

- ‘(a) Develop, adopt and implement a strategy for full inclusion of organizations of persons with disabilities from the early stage of all political decision-making relevant for persons with disabilities across all sectors including implementation and monitoring of the Sustainable Development Goals;
- (b) Provide sufficient financial support for the capacity building and autonomous participation of those organizations in all decision-making.’

Concluding observations on Lithuania
April 2016

PARTICIPATION IN MONITORING AT NATIONAL LEVEL

- **Legislation & policy:** Establish an independent monitoring body in line with the Paris Principles
- **DPO participation:**
 - ensure, as a priority, the full participation of people with disabilities and their representative organisations in the monitoring process
 - set up an independent monitoring mechanism with permanent consultation of DPOs
- **Resources:** allocate the necessary resources to the independent monitoring mechanism (in line with the Paris Principles) to fulfil its mandate of effectively monitoring implementation of the CRPD.

PARTICIPATION IN MONITORING AT NATIONAL LEVEL

CRPD Committee's recommendations

“to provide organizations of persons with disabilities and other civil society organizations with **adequate resources** to enable them to participate fully and effectively in the national implementation and monitoring process”

The Committee expressed concern that an independent monitoring body lacked “outreach possibilities to rural areas. The Committee is also concerned that organizations of persons with disabilities and other civil society organizations do **not receive sufficient support** from the Government to enable them to participate in national implementation and monitoring.”

Concluding observations to Germany in 2015

PARTICIPATION IN MONITORING AT NATIONAL LEVEL

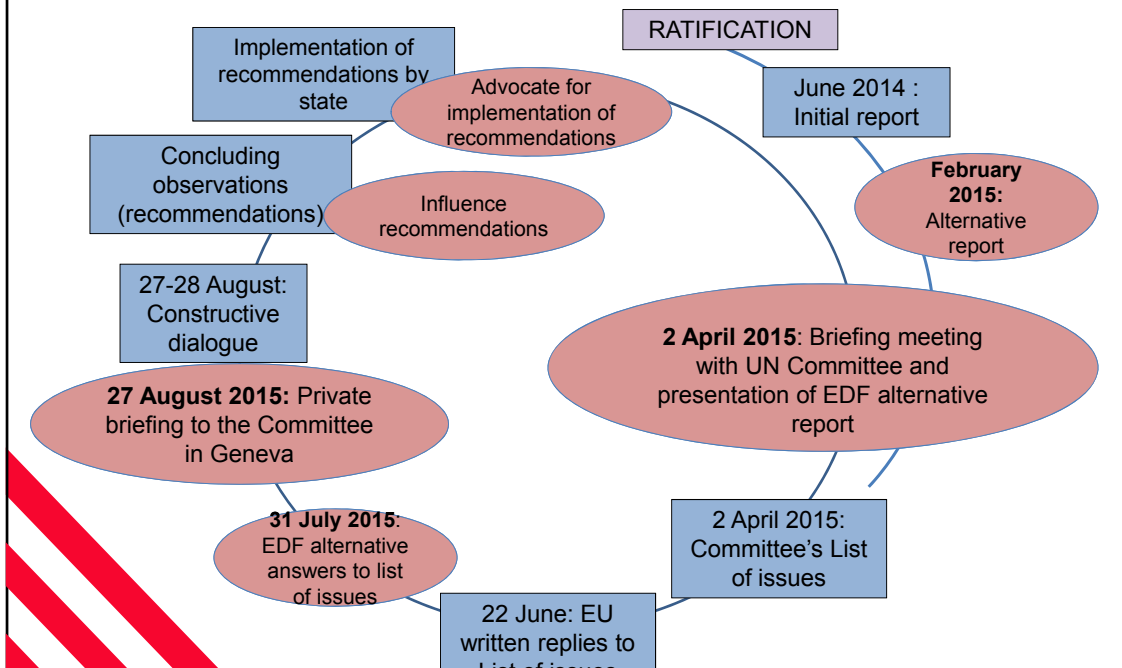
- Most monitoring bodies in the EU involve DPOs
- For example:
 - In Italy and Slovenia a third of the members of the monitoring body are representatives of DPOs
 - In Slovakia it is half of the members of the monitoring body who represent DPOs.
 - In the Lithuanian Council for Disability Affairs, one part of a two-body monitoring body , half of the Council members are DPOs.
 - In Denmark, DPOs are represented on the board of the Danish Institute for Human Rights, as well as in the Council for Human Rights which discusses the work of the institute.
 - Spain is the only example where a DPO forms itself the monitoring body
 - At the EU level, EDF is a member of the monitoring framework (together with the Fundamental Rights Agency, European Ombudsman and the European Parliament)

PARTICIPATION IN INTERNATIONAL MONITORING

Example of the European Disability Forum and its members

- EU submitted its first state report in June 2014 to the UN
- UN CRPD Committee reviewed the EU in April and August 2015
- EDF and its members drafted an alternative report, proposals for list of issues and alternative answers to list of issues
- EDF presence in Geneva – 3 side events in April and August 2015 to brief the Committee on EDF priorities
- Concluding observations adopted in September 2015
- Clear roadmap for implementation of CRPD in the coming 4 years, and basis for EDF and members' EU and national advocacy work

Opportunities for DPOs: EDF plans in EU review process



CRPD COMMITTEE CONCLUDING OBSERVATION TO THE EU

Article 4, 3 CRPD

- The Committee is concerned at the lack of a cross-cutting, overarching framework for consultation among different bodies in the European Union and persons with disabilities, including women, and girls and boys with disabilities, through their representative organizations.
- To set up a structured dialogue for persons with disabilities and their representative organisations in all EU decision making processes, with an independent budget and for sufficient funding for consultation with and participation of persons with disabilities.



The delegation of the European disability movement in Geneva

RESOURCES

[UN Special Rapporteur on the Rights of Persons with Disabilities report on participation in decision making](#)

[EDF Alternative report](#)

[EU report and the UN Committee List of Issues](#)

[CRPD Committee concluding observations to the EU](#)

Library with EDF position papers on www.edf-feph.org

THANK YOU FOR YOUR ATTENTION!

QUESTIONS and COMMENTS ?

Please feel free to contact me at
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EUROPEAN DISABILITY FORUM

.....
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Forum