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Speakers' presentations



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

## SEMINAR FOR POLICY PRACTIOTIONERS

Trier, 13–14 November 2017

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**The seminar by Academy of European Law ERA in Trier**
**EU DISABILITY LAW AND  THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES**
**On 13 November 2017**

# THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES OF THE UNITED NATIONS
## KEY FEATURES

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**Member of Kaunas L'Arche Community**

**Member of the Lithuanian Human Rights Centre**

# MY PERSONAL & PROFESSIONAL BACKGROUND

- ✓ **Personal is political / Political is personal**

- ✓ **Special education vs L'Arche Community**

- ✓ **Policy making through research**

- ✓ **Personal experience of disability**

- ✓ **Member of the CRPD**

# MORE THAN 10 YEARS OF THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES
## Some observations and concerns

- ✓ **Aim and message of the Convention**

- ✓ **Systemic and comprehensive discrimination and exclusion of persons with disabilities**

- ✓ **Charity & medical models of disability, treatment and prevention of disability**

- ✓ **Segregation, violence and poverty as an outcome of disability-based discrimination**

- ✓ **Lack of access to and accommodation at mainstream education, open labor market, quality health service, cultural, political and other areas**

- ✓ **Lack of legal obligations and effective political strategies and action plans ensuring rights of persons with disabilities**

- ✓ **Lack of full and equal involvement of persons with disabilities in policy and decision making, implementation of the Convention and its monitoring**

# WHEN FACTUAL RITGHS HIT ITS LIMITS
## The critical cinema

**The Movie „The Grown-Ups" by Maite Alberdi, Chile/The Netherlands/France, 2016**



I love that man, such a hunk.
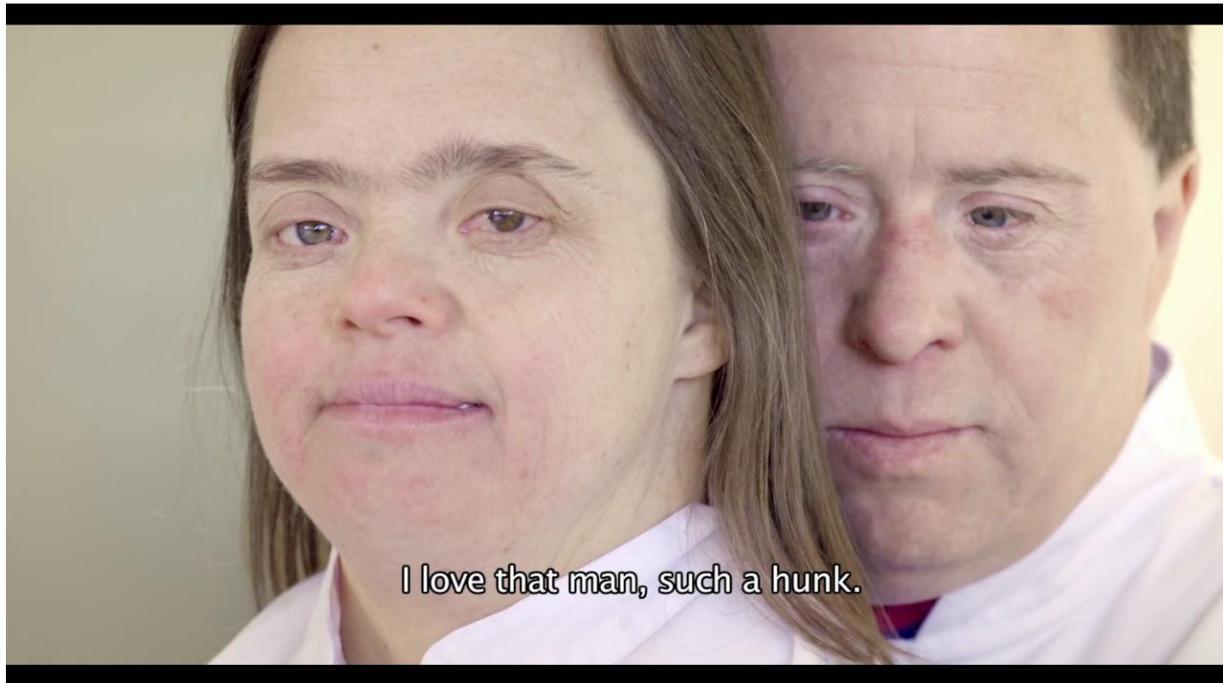
**Structural barriers to adulthood for persons with Down's Syndrome**

**Ricardo: I want a normal life as I never had before**

**No country for persons with intellectual/learning disability**

# KEY CONCEPTS AND CROSS0-CUTTING ISSUES OF THE CONVENTION

- ✓ **The United Nations Convention on the Rights of Persons with Disabilities identified disability as an international priority area**

- ✓ **Dignity as fundamental human right and anchor of the concept of disability (art. 1)**

- ✓ **Persons with disabilities who might be particularly vulnerable to discrimination and abuse of rights: women with disabilities and children with disabilities (arts. 6 and 7)**

- ✓ **Cross-cutting issues: Disability based discrimination (Art. 2); Inclusion and full social participation (art. 3); Equality and non-discrimination (art. 5); Accessibility (art. 9)**

# CIVIL AND POLITICAL RIGHTS OF PERSONS WITH DISABILITIES
and challenges for implementation

- ✓ **Art. 12 - Equality before the law: all persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life**

  Take into account the the Committee's General Comment No 1

- **Art. 14 – Liberty and security of the person: to repeal provisions which allow for involuntary commitment of persons with disabilities in mental health institutions based on actual or perceived impairments**

  Take into account the Guidelines by the Committee on the article 14

- **Art. 29 - Participation in political and public life: to guarantee the right to vote independently by ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to use for all persons with disabilities**

# ECONOMIC, SOCIAL AND CULTURAL RIGHTS OF PERSONS WITH DISABILITIES
## and challenges for implementation

- ✓ **Art 19 – Independent living and inclusion in the community: Deinstitutionalization, access to all services in community and personal assistance**

  Take into account the the Committee's General Comment No 5

- ✓ **Art. 24 – Inclusive education and : strengthening the capacity of the mainstream education system to reach out to all learners**

  Take into account the the Committee's General Comment No 4

- ✓ **Art. 27 – Work and employment: to ensure accessibility and implement reasonable accommodation in open labor market**

# SPECIFIC RIGHTS OF PERSONS WITH DISABILITIES
## and challenges for implementation

✓ **Art. 31 - Data and statistic: take into account the Washington Group Short Set of Questions on Disability**

✓ **Art. 33 - National implementation and monitoring: independence, sufficient funding and full involvement of organizations of persons with disabilities**

Take into account the guidelines on independent monitoring frameworks and their participation in the work of the Committee

# RELATION TO OTHER HUMAN RIGHTS AGENDAS AND TREATIES

- ✓ **Sustainable Development Goals:**

  SDGs' targets 10.2 and 10.3 to article 5 of the Convention
  targets 5.1, .5.2., 5.5. to article 6
  targets 9, 11.2 and 11.7 to article 9
  target 16.3 to article 16
  target 16.3 to article 17
  targets 4.5 and 4.8 to article 24
  target 3.7 to article 25
  target 8.5 to article 27
  targets 1.3 and 10.2 to article 28
  target 17.18 to article 31

- ✓ **Sendai Framework for Disaster Risk Reduction 2015 – 2030**

- ✓ **Istanbul Convention, Council of Europe Convention on preventing and combating violence against women and domestic violence**

- ✓ **Council of Europe Committee on Bioethics:** Draft Additional Protocol to the Oviedo Convention on Human Rights and Biomedicine

# THE ROLE OF ORGANISATIONS OF PERSONS WITH DISABILITIES DPOs

✓ **Article 4.3. General obligations**

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

✓ **Article 33.3. National Implementation and monitoring**

Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

✓ **Article 35.4. Reports by States Parties**

… 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 present Convention.

Alternative reports by DPOs

# THE ROLE OF THE CRPD COMMITTEE
## Article 36

- ✓ Receives and reviews official and alternative reports from States parties
- ✓ Holds constructive dialog with the State parties, provides them with concluding observations that include its concerns and recommendations
- ✓ Holds days of general discussion on critical issues. The Committee has already held days of discussion on the articles 12, 9, 6, 24, 19 and 5
- ✓ Adopts general comments that are authoritative statements on particular themes or articles. General Comments on articles 12, 9, 6, 24, 19
- ✓ Meets representatives of DPO's, NHRI's and UN agencies to discuss issues related to the implementation and monitoring of the Convention
- ✓ Coordinates with other treaty bodies to mainstream the disability rights in all other human rights policies and related documents
- ✓ Receives communications (complaints) and issue recommendations on these communications
- ✓ Undertake inquiries into countries when there is reliable information indicating grave or systematic violations of the Convention

# Ačiū    Merci   Thank You



Picture: „The Grown-Ups" by Maite Alberdi, Chile/The Netherlands/France, 2016

# The legislative phase of the implementation of the UNCRPD

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Directorate general Persons with Disabilities
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Belgium

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# The legislative duties of the States parties to the UNCRPD

- The Convention requires Stats parties to adopt a number of specific legislative steps to fulfil their obligations under the Treaty.

- Article 4 of the UNCRPD contains the overarching general obligations requiring the adoption of legislative measures:

*1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:*

*(a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;*

*(b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities...".*

- In addition to this general reference, the UNCRPD also contains a number of specific references to the need for legal guarantees of particular rights. For example, article 15 requires States parties to take "all effective legislative" and other measures to ensure persons with disabilities are not subject to torture or other forms of cruel, inhuman or degrading treatment.

- It is also clear from the provisions of a number of other articles of the UNCRPD that legal protection of specific rights is required. For example, the guarantee in article 12 that persons with disabilities have the rights to recognition as persons before the law and to enjoy legal capacity on an equal basis with others and the requirement that any measures relating to the exercise of legal capacity are subject to review by a competent, independent and impartial authority or judicial body can only be effectively guaranteed if embodied in law.

- It follows both from article 4 of the UNCRPD and from the obligation of a State party to report regularly on progress made in implementing the UNCRPD that a comprehensive review of the situation under existing legislation is required once a State has become a party to the UNCRPD.  This implies the ability to identify, amend or repeal properly the provisions which are inconsistent with the UNCRPD and the introduction of new legislation to cover areas that are not adequately covered under existing laws.

# The implementation of the UNCRPD as a policy cycle

The duty of the Member states goes beyond merely enacting new pieces of laws.  Actually, the process of implementing the UNCRPD, like any other policies, can be best understood as a cycle comprising the following various typical and interlinked stages :

- Policy initiation : the policy process starts with the ratification of the UNCRPD. States parties have to undertake a general review of their disability policies.
- Policy formulation : after a review of available options, specific policy responses are drafted into legislation (in a narrow sense, this is the legislative phase).
- Policy  implementation : plans, programmes and project are designed and executed  to implement the legislation.
- Policy monitoring and evaluation :  at this stage of the process, implemented activities are monitored and their outcomes are  assessed.

# The purpose of the legislative phase

- The purpose of the legislative phase of the implementation of the UNCRPD is to translate a policy decision into a legislative solution that will achieve the objectives set out by the provisions of the UNCRPD.

- Therefore, although there is no single understanding of quality in legislation, everyone agrees that a "good law" must be in first instance effective.

- As far as effectiveness is concerned, distinction can be made between :
    - a "political" effectiveness which can be defined as the degree to which the legislation at EU or national level embodies the values and standard the UNCRPD.
    - a "formal" effectiveness which can be defined as the degree to which the key provisions of the legislation are practically enforced and complied with.
    - a substantive effectiveness which can be defined as the degree to which the legislation and the practical application of the measures at EU/national level produce a real change for the target groups.

- In principle, the ultimate test for a legislation aiming at implementing the UNCRPD should be its substantive effectiveness which should be established by the extent of the causal relationship between the purpose for creating the legislation and its effects on the life of persons with disabilities.

# Applying the principles of legislative quality

According to legislative theory, the features of an effective legislation and the fundamental process of law-making can be analysed irrespective of any policy issue , legal tradition or the structure, size, level and procedures of the legislative and governmental systems. The methodological approach commended for elaborating effective pieces of law is based on the separation of different analytical steps or sequences. These steps include :

1. The analysis and definition of the problem that the legislation presumes to solve;

2. The determination or clarification of the goals of legislation;

3. The examination of legal instruments or means that can be used to solve the problem and the choice of such instruments;

4. The drafting of the normative content;

5. The formal enactment;

6. The implementation;

7. The monitoring and the evaluation.

## The analysis and the definition of the problem

- The first step of the process of drafting effective legislation of  is identifying and analysing the real problem that requires governmental action and its derivative broad policy objective, which may be suitably addressed through means of policy intervention.
- Inadequate problem identification leads to :
  - focusing on effects of problems :
  - making unrealistic, irrelevant, wrong interventions.
- Adequate problem analysis help to define objectives and priorities and choose appropriate means
- In various respects, problem analysis is the most critical stage of the process and guides other consecutive steps.

## Disabilities (impairments) are not the problem

- As far as problem definition is concerned, it should be stressed that the UNCPRD adopts a social model-based understanding of disability where "disability" is seen as the result of the way in which social or other environmental factors interact with a person's impairment so as to disadvantage or exclude that person from the enjoyment of rights and opportunities.
- This view goes against the conventional legal thinking which tends to see the exclusion of persons with disabilities as regrettable but inevitable. Traditional law views as a consequence of fate and not as a matter within its control that many persons with disabilities are unable to enter the physical and social structures built for everyday life. These problems can't therefore be recognized as a violation of the principles of  human rights.
- The human rights approach that underpins the UNCRP confronts such view. This approach sees persons with disabilities as individuals whose rights are been violated, seeks to understand why they are unable to enjoy their rights, and redress unjust distributions of power that impede their participation in the society. In this sense, it identifies persons with disabilities as rights-holders and defines their entitlements and the corresponding duty-bearers and their obligations,

## Giving affected people a voice

- Article 4. 3 of the UNCRPD states that "*In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations*".

- Involving organizations of persons with disabilities in the legislative process before decisions on legislation are made is not only an issue of compliance with a general obligation of the Convention but an essential practice in the determination or the clarification of appropriate goals of a legislation.

- Consultation provides first data and information on the situation on the ground and thus can link legislative initiatives with reality. Consultation can also prove useful for identifying the specificities and needs of the target groups.

- Building consultation and participation procedures into the process of designing and implementing disability legislation can have a positive impact on the legislation's quality and its capacity to deliver results.

## The design and the writing of the legislation.

- Understanding what the law prescribes is a fundamental premise of the rule of law; the opposite of this leads to confusion, informality, and lack of accountability. Disability legislation should be made should be clear, accessible, and understandable to all : as well to persons with disabilities as right holders as well as to the various duty bearers.

- However, in the practice , the constant introduction of new disability legislation makes efforts at ensuring the clarity and accessibility of the law a major challenge. Because of the incremental character of the policy process, legislation is often incomprehensible, fragmented, and dispersed is inaccessible to the target groups and even to trained jurists.

- There are also numerous examples of inconsistencies between disability laws, conflicting definitions of disability or disability definitions used in different ways or not at all that make understanding and interpretation complicated. At European level, this problem is clearly illustrated by the case law of the European Court of Justice which reveals that there is a widespread legal confusion on the different meanings of disability.

## The choice of the policy instruments

- The selection of the policy measures should depend on what the problem to be addressed is supposed to be about, what kind of measures and process is appropriate to that target, and what the costs of implementation and enforcement will be.

- Changing social norms usually takes a long time. Behaviours that are relatively uncomplicated and clearly defined are generally easier susceptible to be implemented by laws. Laws that try to control complex processes will themselves have to be very complex and entail high enforcement costs.

- This could be particularly the case in implementing many aspects of the UNCRPD such as equal recognition before the law, universal access, inclusive education or the right to community living. Such laws require complex changes in personal, market, and institutions behaviour and practices to attain.

- In the context of the UNCRPD, instrument choice should never be about selecting a single instrument to address a single issue. Disability rights issues come almost always in complex matrixes, and policy responses usually should consist of a matrix of instruments.

## The implementation of the legislation

- A high proportion of laws do fail to meet with their objectives because, either they are not at all or only partially implemented, either they are carried out in such bad way that they still fails to produce the intended outcomes. Many studies refers to the "implementation gap" for describing the divide between the intended and the achieved outcomes of the legislation.

- However, a good law should be implementable. Disability laws often seek to achieve ambitious and radical reforms without considering the resources and infrastructure required for their implementation. Legislators may assume that the administration will automatically adapt to ambitious provisions even though institutional capacity and resources might be lacking. These create laws that become effectively unusable, cannot be properly implemented, and are incapable of delivering intended results.

- Institutional and financial capacity, coordination mechanisms, roles, and functions need to be considered early in the process of law making. Enforcement and implementation do not come about magically—they do so only when they have been clearly considered in the planning, designing, and drafting of legislation.

## The implementation as an adaptive challenge

- Effective implementation requires  to get the technical aspects of law making  right : defining the problem correctly,   using appropriate consultation  mechanisms, selecting the relevant instruments, designing and writing accessible norms and aligning and coordinating the resources and activities for implementation.

- But it is also just as important to have strong leadership qualities  invested in the implementation so that they facilitate positive change in the behaviour or conditions of the target groups.  People need to be brought along in the change process. This is done by displaying social skills, activating existing sources of authority, and using sources that legitimate the change and resonate with  values on the field.

- Implementation can thus be viewed both as a technical and an adaptive issue, requiring an understanding of the current problem and exercising skills to affect behavioural and social change. Implementation must thus be viewed much a social process as it is a technical process.

## Disability policy  implementation as a multi-sectoral and multi-institutional challenge



**Sectoral policies**

Employment  Education  Public health

Social care  Housing

Social Security  Justice affairs

Consumer Affairs  Transportation

**Institutional levels**

International level

National/federal level

Regional level

Local level
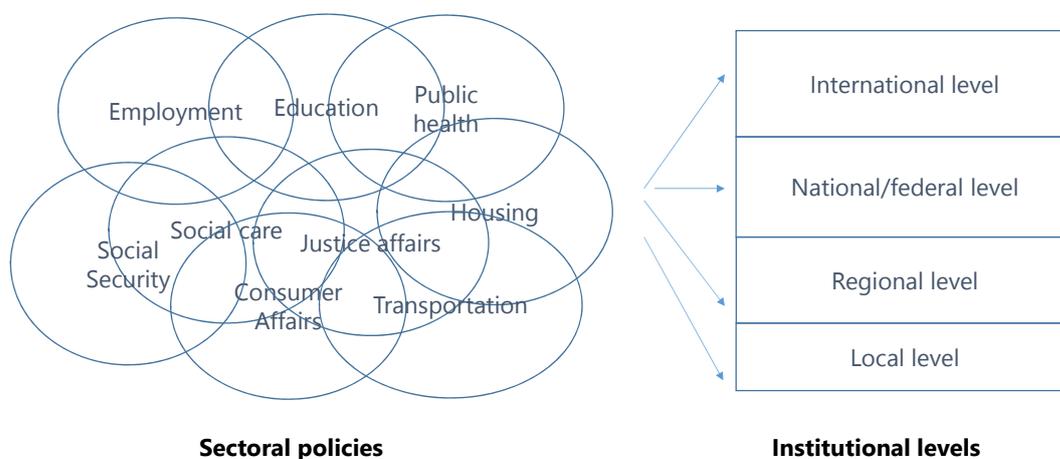
## The monitoring and the evaluation of the legislation

- Article 33 pf the UNCRPD mandates the State Parties to monitor the implementation of the UNCRD by three mechanisms . First, States have to designate one or more focal points within government for matters relating to implementation; second, States have to give due consideration to the establishment or designation of a coordination mechanism within government to facilitate action across sectors and at different levels; and third, States have to establish or designate a framework that includes one or more independent mechanisms to promote, protect and monitor the Convention's implementation.

- Regardless the UNCRPD, the need to monitor the implementation of a legislation and evaluate its results is a requirement linked y to the democratic principles of legality, transparency and accountability.

## Concluding remarks

- Its acknowledged that the legislative phase of the UNCRPD can be a difficult, complex and sometimes an unpredictable process. As every law making process, it can also be subject to policy compromise that relates to political sphere and implementation measures can be hampered by budgetary and personnel deficiencies.

- Nevertheless, the application of the principles of legislative theory through evidence-based law making, taking into account the voice of persons with disabilities in conjunction with facilitating compliance by making legislation clear, simple, and accessible, and paying attention to the implementation in the planning stages. may improve and facilitate the domestic implementation of the UNCRPD provisions, in a way that such legislation is more likely to attain its ultimate objectives.

How to conduct a disability impact assessment

- An integrated, systematic and cross-departmental process of inquiry that takes the rights of people with disabilities into account in formulating, implementing, and evaluating policies.

- Inclusiveness and effectiveness of the public policy

- Horizontal and vertical coherence of the public policy

# Example

- [http://www.justice.ie/en/JELR/20120305%20DIA%20Guidelines.pdf/Files/20120305%20DIA%20Guidelines.pdf](http://www.justice.ie/en/JELR/20120305%20DIA%20Guidelines.pdf/Files/20120305%20DIA%20Guidelines.pdf)

**How to Conduct a Disability Impact Assessment**

Guidelines for Government Departments

AN ROINN DLÍ AGUS CIRT AGUS COMHIONANNAIS
DEPARTMENT OF JUSTICE AND EQUALITY

# CASE STUDY

PROPOSALS FOR NEW REGULATIONS TO IMPROVE THE QUALITY OF LONG TERM CARE

10 reasons why neglect and abuse of PLWD may be the norm rather than the exception in LTCFs

my Alzheimer's story

Bottom line

Ageism/ stigma

Few police/ small sticks

Biomedical model

UNcare cultures

Systemic institutional neglect and abuse of elderly PLWD

Poor leadership

Dis-incentivized workers

Lack of training & understanding

Warehouse environments

Staff/ resident ratios
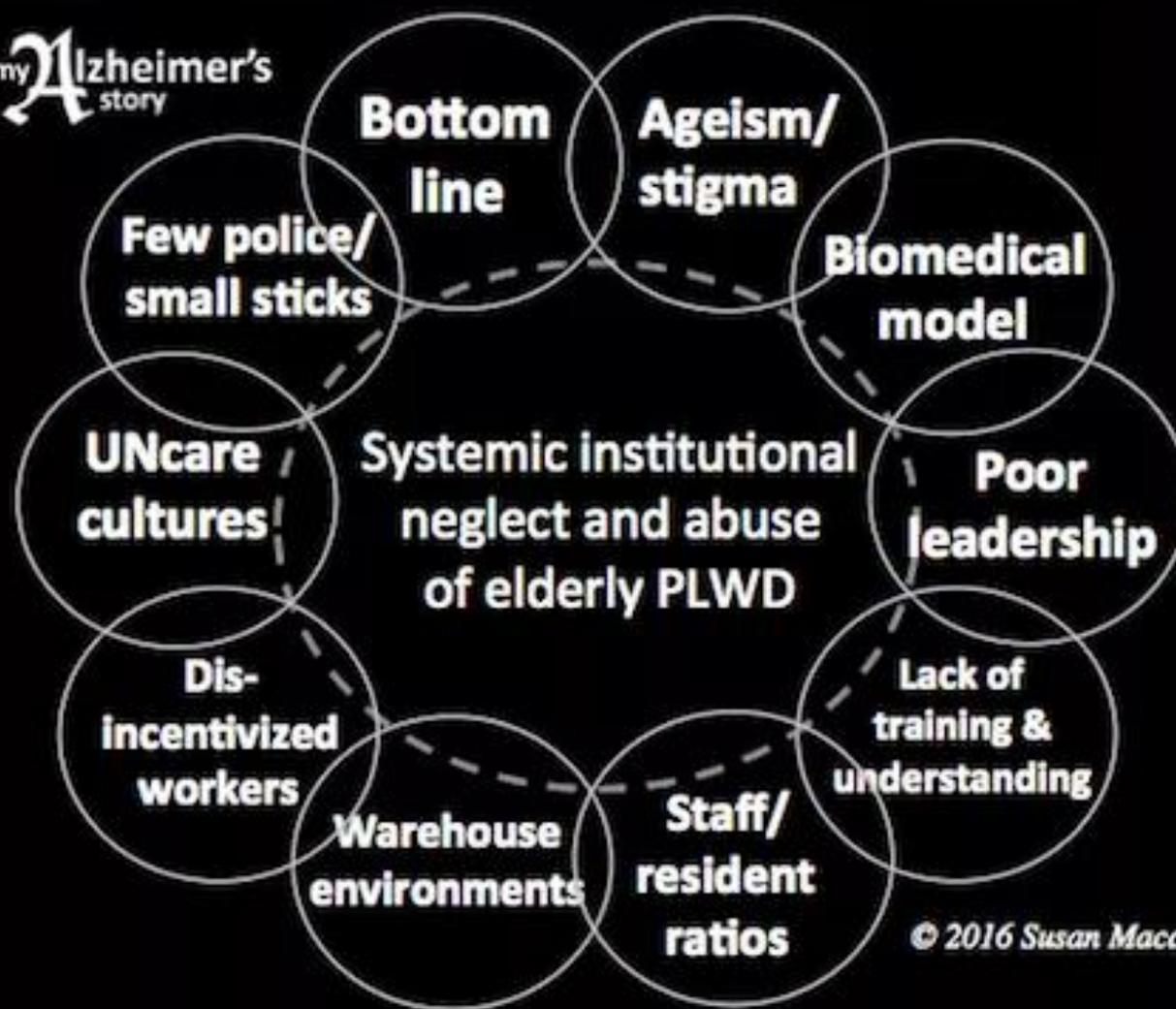
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<div align="center">**THE DISABILITY IMPACT ASSESSMENT**</div>

**Purpose**

- A disability impact assessment is an integrated, systematic and cross-departmental process of inquiry that takes people with disabilities into account in formulating, implementing, and evaluating policies.

**Rationale**

- Public policy should benefit all citizens. Many policies which do not incorporate a gender analysis have historically had a negative impact on girls and women. It is the same for people with disabilities. Unless the policy process looks at policy goals, programs and outcomes from the vantage point of people with disabilities in all their diversity (e.g. gender, ethno-racial-cultural status) , the barriers people with disabilities face will remain in place and largely invisible.

- Policy development to advance full inclusion requires vertical and horizontal coherence. The barriers and inequalities people with disabilities face do not fall neatly into one policy area. Addressing barriers to education, for example, requires policies that cut across many domains. The disability impact assessment aims to examine the incentives and disincentives for achieving policy coherence between policies within and across departments at one level of government (horizontal analysis); and coherence between policies at different levels of government (vertical analysis).

**Values and assumptions underpinning**

The Disability Impact Assessment involves critically examining the values and assumptions which guide and underpin policies. Sometimes the underlying assumptions have never been made explicit, and have been inherited from earlier perspectives about disability which are no longer consistent with the vision for full inclusion, participation and accessibility. The process for policy analysis should consciously surface underlying values and assumptions regarding disability to see if they are consistent inter alia with the following starting points:

- **Dignity** : disability should be understood from a social and human rights perspective. Policy development is often incremental, building on existing policies, many policy proposals are still guided by outdated models of disability.

- **Autonomy**: in a democratic society, all citizens, including people with disabilities, should be supported to develop and pursue their own vision of a good life – individually and collectively – provided it does not bring harm to others.  Policy proposals should be examined to ensure they are providing people with disabilities equal access to the public goods required to pursue and realize a personal vision of a good life.

- **Diversity** :  all people have a unique developmental path – diversity is the only norm. There is no 'normal'. Normalcy is the statistical effect of drawing a bell curve. A central goal of public policy is to create the conditions for each citizen to maximize his or her developmental potential along their unique path.

- **Equality** : achieving equality does not necessarily mean treating everyone the same. People with disabilities may require unique support arrangements to participate in education and the labour market. The focus must be on the outcomes recognizing that different people may require different inputs.

- **Participation** : participation is the starting point for a democratic society. Democracy cannot be achieved without full social, economic, cultural and political inclusion of all citizens. As such, it is fundamental to good governance to develop and implement policies that result in inclusion of all. To do so requires understanding the unique circumstances and barriers to inclusion that different population groups face. Because people with disabilities have faced historic disadvantage it is incumbent on governments to examine the sources of this disadvantage and ensure public policies address them.

**Guiding Questions for the assessment**

- The process involves asking questions about policy proposals in order to ensure they maximize the potential for people with disabilities to be fully included.

- For each question, ask a further one: on what evidence is the answer based ? Therefore, answering these questions may entail, among other things, gathering or requesting evidence from previous studies and reports, reviewing data, conducting analyses of proposed and final policy pronouncements, and conducting surveys of stakeholders.

- Answers to the set of questions are not 'right or wrong.' Rather, they provide information on which policy makers should be able to revise their legislation to result in more inclusive outcomes.

| Policy vision and goals | In what ways does the vision, goals of the policy proposal, directly or indirectly, affect people with disabilities ? |
| --- | --- |
| | What are the underlying values and assumptions of the policy and are they consistent with full inclusion and participation |
| | Are policy goals framed in inclusive ways? |
| | Are policy goals based on evidence and reflective of good practices that address the needs of and barriers faced by people with disabilities? |
| | Have people with disabilities and their families, and their organizations, effectively participated in identifying their needs, barriers experienced, and desired policy goals? |
| Proposed policy measures | Is the design of the provisions consistent with relevant Articles of the UNCRPD? For example: Is the program designed on the basis of Article 3 (Principles), Article 4 (General Obligations) and other Articles specific to the policy/program area? |
| | Have the overriding problem and establishing the causes and effects related to that problem correctly been addressed ? Are the provisions designed to address the full range of barriers people with disabilities face in this policy area? |
| | In examining options for the best mix of policy initiatives, identify and describe how each:<br>• enhances self-determination and autonomy;<br>• avoids further stigmatization, isolation or separation of people on the basis of their disability;<br>• serves as an incentive for stakeholders to advance inclusion and universal access in this or any other policy domain;<br>• increases the capacity of community programs and services to include and support people with disabilities;<br>• enhances capacity, knowledge, skills and competencies among key sectors to include and support people;<br>• maximizes efficiencies while providing needed incentives to transition outmoded models of services and support to approaches more consistent with the UNCRPD;<br>• leverages individual, family, community and private sector |

| | |
|---|---|
| | resources without compromising equitable access and outcomes. |
| **Policy coherence** | Is the policy design as it relates to people with disabilities, coherent with policies across the Government? |
| | Does participation in the policy create disincentives for people with disabilities to access other needed programs, benefits or services provided by another level of government (i.e., European, national, regional, local)? |
| | What coordinating mechanisms have been to identify and effectively address horizontal and vertical implications? |
| **Implementation** | What are the respective roles and responsibilities of federal, state, and local agencies for implementation and enforcement? |
| | Do people with disabilities access programmes, services and benefits on an equal basis with others?<br>    • By disability type<br>    • By language, family status, age, gender, ethno-racial-cultural status<br>    • By geography – urban, rural<br>    • Other factors considered relevant |
| | Are all policy documents and communication material (including electronic media, web sites, etc.) fully accessible and available in plain language and alternate formats, and are people informed about this availability? |
| | Are there effective mechanisms for monitoring involving disability organisations and all the other relevant stakeholders? |
| | Is data collected for policy benchmarking monitoring and evaluation? |
| **Evaluation** | Are the criteria against which the policy will be measured and evaluated consistent with the UNCRPD and other relevant human rights instruments? |
| | How will the policy be evaluated against these criteria on an ongoing basis? How will people with disabilities, their families and organizations be involved in this evaluation? |
| | Does participation enable outcomes for people with disabilities consistent with the UNCRPD? If unequal patterns of access and outcomes exist, what factors account for this?<br>    • Lack of reasonable accommodation and disability-related supports<br>    • Costs (e.g., to the individual/family, to government, to service providers)<br>    • Physical accessibility<br>    • Attitudes (of service providers, families, employers)<br>    • Existence of a parallel system<br>    • Lack of affordable, accessible transportation<br>    • Urban/rural differences<br>    • Other systemic barriers |

**PROPOSAL AIMING AT IMPROVING THE QUALITY OF LONG TERM CARE SETTINGS FOR THE ELDERLY IN SYLDAVIA**

**The context of long term care policy in Syldavia**

In the country of Syldavia, the population is rapidly ageing as a result of falling birth rates and rising life expectancy. There is wide consensus that as a result considerable investment will be needed in elderly care. A consortium of research institutes have all predicted that the cost of elderly care will rise by more than 300 per cent in real terms between 2000 and 2050 as a consequence of demographic changes: for example, the number of over-85s - those most likely to need care - is likely nearly to quadruple in the period.

At the same time, Syldavia has developed new approaches to long-term care to respond to the different needs and expectations of citizens, for example: community care services have been extended, more differentiated care services have been installed, and residential care facilities' missions have been adapted

The importance of long-term care services and citizens' expectations of them are rising, and at the same time governance structures are moving towards market-oriented mechanisms. As such, it has become crucial to have effective instruments to define, assess and improve quality in a sector which, notwithstanding important co-payments of users, is still mainly funded by public resources.

Relationships between the federal government of Syldavia which is the main purchaser/regulator of care, regional and local authorities that are mainly co-funders (local authorities) and providers are also changing. radically changed. They take the form of :

- Provisional contracts' between the provider and the regulator which indicate an authorisation of the provider on the basis of a number of basic structural prerequisites.
- Framework contracts' on the regional level between the Federation of Service Providers and the regulator concerning the content of services, financial stipulations (reporting and accounting), personnel levels, and control mechanisms.
- Agreements concerning the funding of services are made between each provider and the regulatory authority on regionally defined 'care packages', i.e. a set of services in which each individual service included is rated by means of points, and individual arrangements.

These agreements stipulate authorised providers should use quality management systems but no specific system or method has been defined. Consequently, many different approaches have been developed. In practice, service providers tend to comply with the necessary minimum standards, rather than actively searching for quality improvements

Important efforts concerning quality assurance and improvement have been undertaken with the establishment of the National Board for Social Care inspection and its operative units on the regional level. The NBSCI is responsible for training and organising medical doctors and specialist nurses who assess the individual needs of applicants for long term care benefits; it also carries out quality inspections with a view to advising Service providers on potential improvements. The NBSCI has the

power to cut payments or exclude care home providers entirely if quality problems are detected, and not rectified within a set period.

Reports of the NSBCI and related research highlight that important quality problems remain in Syldavian care homes concerning both structural, process and outcome quality. For instance, in 2016, prevention and therapy of pressure ulcers was deficient in 35.5% of all inspected care homes; deficits with nutrition and hydration prevailed in 34.4%, while problems with incontinence were registered in 15.5% of all cases.

At the same time, the quality inspections of the NSBCI have triggered a fierce debate about quality in long-term care, mainly between the service provider organisations and the NSBCI – including a number of trials at the social court – concerning the validity of inspection results. There is a concern in de sector that the current regulatory regime is already wide and pervasive. Inspections, targets and assessment criteria are everywhere.


**Aim and content of content of the reform**

The reform of the long term care legislation aims to change the traditional inspection standards strategy and to make the end result are made publicly available in the form of school marks.

The approach will be based on the principles of quality management, a method to ensure and improve structural, process and outcome quality of any kind of service or product on the organisational level. This entails the application of the management cycle consisting in the definition of goals, the planning and organisation of processes to achieve the objectives, the evaluation of the results and the implementation of corrections or further improvements (plan – do – check – act).

The reform will involve an external auditing process (certification) by a third party to control for the compliance with defined standards and the achievement of defined outcomes. The external assessment that will be introduced will be based on a set of indicators to assess the outcomes of long-term care facilities. These indicators are supposed to be evidence-based, applicable to daily practice, suitable for internal quality management, and verifiable on inspection. They should also avoid, as far as possible, making bold claims which are not comparable between care homes.

After a trial in several facilities, the six following important domains have been selected from a pool of possible areas :

- Functional outcomes: the maintenance and promotion of autonomy in day-to-day living;
- Individual safety: protection of residents against risks, injuries and burdens;
- • Accommodation and household assistance;
- • Activities and communication
- • Responses to difficult situations (for instance, in the case of residents who have psychological problems);
- • Information gathered through contact with the residents' relatives, using surveys or other methods.

The results obtained under these criteria will be compared over an interval of six months.

The results for each domain as well as the end result are made publicly available in the form of school marks ). These guidelines are supposed to ensure accessible data for users or potential users to judge the quality of each care home. T

Once enforced, this approach is expected to act as a stimulus to improve internal quality management, encourage more effective use of the resources devoted to quality assurance, generate more objective public discussions of care quality, and valid information on quality for (potential) users of long term care.

The implementation costs of the indicators (on average about €5000 per care home) and the number of skilled inspectors necessary to carry out yearly inspections by the NSBC — in about 11,000 care homes and 12,000 plus home care providers will be financed in the framework of the LTC Insurance, but for the long-term sustainability of the approach, inspections could be reduced — for instance in well-performing care homes.

# The monitoring phase of UNCRPD implementation under Article 33:
## A unique opportunity to make disability rights real

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13 November 2017

# Overview

1. Article 33 CRPD (normative content, interpretation, relevance)

2. Policy context: how to assess the implementation of Article 33?

3. Links with Article 4(3) CRPD

4. Challenges: Article 33 in the Concluding Observations of the UN CRPD Committee

5. Some (promising) practices on implementing Article 33

6. Criteria for meaningful civil society participation

# 1. Article 33 of the CRPD: National implementation and monitoring

**Article 33(1)**

'States Parties, in accordance with their system of organization, shall designate **one or more focal points** within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a **coordination mechanism** within government to facilitate related action in different sectors and at different levels.'

# Interpretation of Article 33(1): focal point(s)

- Focal points are issue of internal public administration
- Have to be formally designated (one, or more)
- Should be close to the central authority
- Ministries that are suitable to deal with disability in light of the human rights model of disability (e.g. Ministry of Justice)
- Engaged and trained staff on CRPD provisions
- Adequate resources

# Interpretation of Article 33(1): coordination mechanism

- Not an obligation under the CRPD – but essential for successful implementation

- To facilitate co-operation between different layers and sectors of public administration

- Advantage of a good coordination mechanism: easier to avoid adopting isolated measures in different government departments

# Article 33(2)

'States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, **a framework, including one or more independent mechanisms**, as appropriate, to **promote, protect and monitor** implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.'

# Interpretation of Article 33(2)

- A framework including one, or more independent elements to ensure accountability of the State and impartial monitoring

- 'Independence' is understood in line with the **Paris Principles**

**National Human Rights Institutions** (NHRI),

(or **Ombudsman**)

- UN Paris Principles (1991) provide benchmarks for NHRIs to be accredited and define the level at which they can participate

# National Human Rights Institutions (NHRI)

- At the intersection of state and civil society to assure State's compliance with their international legal obligations

- Bridge between international norms and local implementation

- Established by law, or decree to promote and protect human rights

- Formal independence, sufficient resources, close relation to civil society

- Pluralistic representation of social forces in membership

- Accreditation (A, B, or C status) by International Coordinating Committee (ICC)

# Promotion, protection, monitoring

| Promotion | Protection | Monitoring |
|---|---|---|
| Scrutiny of draft/existing legislation, regulations, practices | Investigation and examination of individual and group complaints | Assess the implementation and adaptations of CRPD provisions at domestic level |
| Awareness-raising campaign | Litigation | Collection of data on human rights violations |
| Research | Conducting of enquiries | Development of indicators and benchmarks to measure progress |
| Human rights education | Filing amicus curae briefs | Visiting places where violations often occur |

**Doesn't require full independence**          **Requires full independence**          **Requires independence**

# Article 33(3)

'**Civil society**, in particular persons with disabilities and their representative organizations, shall **be involved and participate fully in the monitoring process**.'

# Interpretation of Article 33(3)

- Consensus on this provision during CRPD negotiations

- Civil society involvement, in particular representative organisations (DPOs)

- Truly innovative element: requires new forms of collaboration with the State, but also with the human rights system

- Bringing the grass-root experience in CRPD monitoring

- Need for capacity building and great understanding of CRPD provisions

- Cross-disability and cross-society focus

# Triangulation of Art. 33: Balance of power and functions
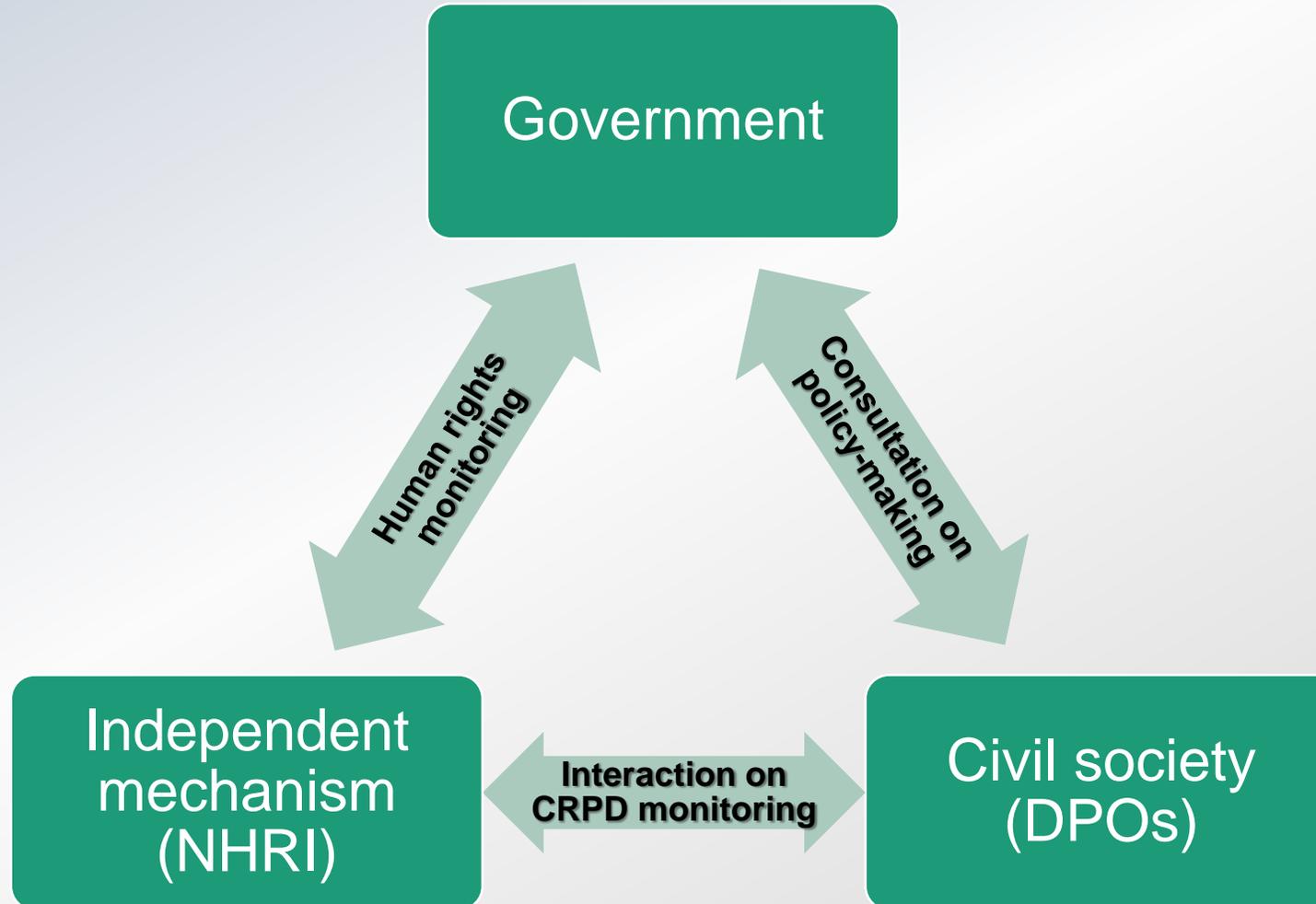
# Background for Article 33 CRPD

- Most comprehensive provision on national-level implementation and monitoring ever included international human rights treaty

- To give appropriate answer to the critics towards the UN – Treaties don't generate real change in people's lives

- Willingness of the Ad Hoc Committee to create an innovative system during the drafting of the CRPD

- Tool to narrow the 'implementation gap' in international human rights law

# 2. How to assess the implementation of Art. 33?

# 3. Article 4(3): Full participation in policy and decision-making

**Article 4(3)**

'In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties **shall closely consult with and actively involve persons with disabilities**, including children with disabilities, through their representative organisations.'

# Interpretation of Article 4(3)

- New space between the State and Disabled People's Organisations

- Compensate for past exclusion of persons with disabilities

- Opportunities & new challenges for the disability movement

- No instructions in the CRPD on how to establish partnership between policy-makers and DPOs?

- When does involvement start? Participation in all levels? What is active and effective participation?

# 'Participation' in the UN CRPD

1. **Drafted in a participatory way:**

- Active involvement of the disability movement

- International Disability Caucus – huge impact

- 'Nothing about us without us!'

2. **'Participation' as a leitmotiv in the whole Treaty:**

- More than 30 mentions

# Participation - Inclusion

'Participation is a broader demand, made not only the state but also to society, to allow persons with disabilities to fully become members of the society and the various communities of which they are part'. (Mégret)
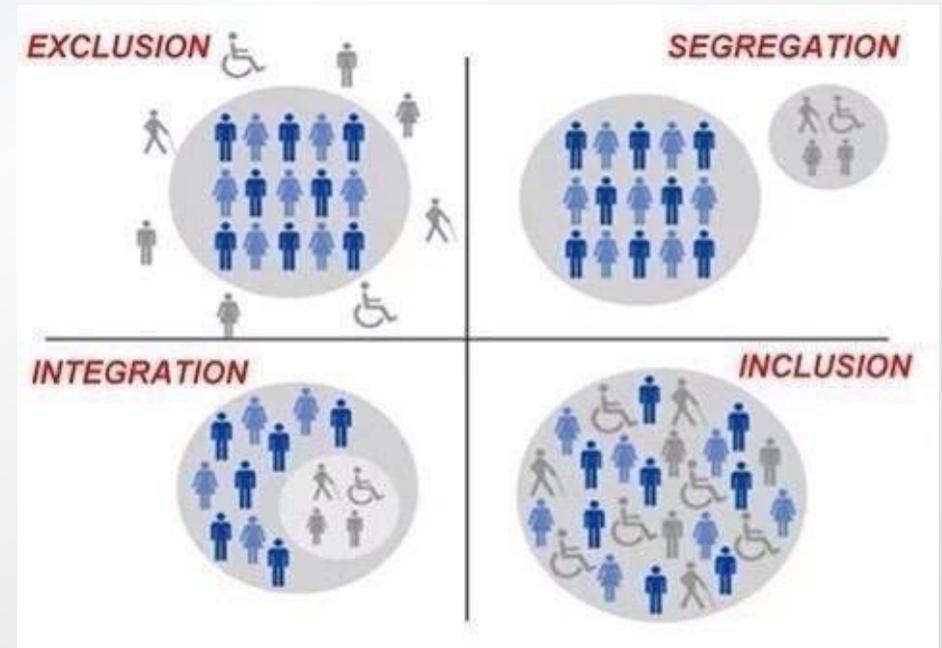
# 4. Article 33 in the Concluding Observations of the UN CRPD Committee

## General trends

- Up until today 61 Concluding Observations by the Committee
- Article 33 mentioned in 60 COs
- Only 4 States Parties established a CRPD compliant monitoring framework
- 22 States Parties haven't established any monitoring mechanism

## Common remarks

- Increasing focus on lack of resources to effectively monitor
- Comments on lack of focal points + coordination mechanism Art.33(1)
- Lack of involving NHRI in monitoring/lack of capacity to monitor
- Lack of involving organisations of pwd in monitoring (in 44 COs)

# Challenges in implementing Article 33 in a CRPD compliant way at national level

- Complexity of policy and law-making processes

- Cross-cutting implementation - coordination

- Formal establishment of independent monitoring framework

- Allocation of sustainable funding

- Lack of a Paris Principles compliant, independent NHRI

- Involvement of all organisations representing persons with disabilities – heterogeneous movement

# 5. Some (promising) practices of implementing Article 33

**New Zealand**

- CRPD ratification: 25/09/2008
- Focal point: **Office for Disability Issues**
- Coordination mechanism: **Ministerial Committee on Disability Issues**
- Article 33(2) framework: **Human Rights Commission**, **Ombudsman**, **Convention Coalition** (group of DPOs – Article 33(3)
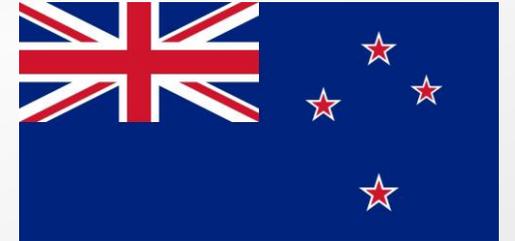
# New Zealand
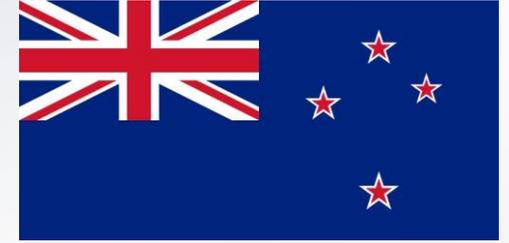
## Strengths:

- 'Best-looking' structure to implement Article 33(2)
- Government's willingness harmonize implementation across ministerial departments
- Commitment of the government to make a change together with civil society
- Available government funding for Convention Coalition

## Challenges:

- No systematic monitoring carried out by the Article 33(2) framework
- Low awareness of its function among member organizations
- Indigenous people with disabilities felt excluded from the CRPD and its implementation (collective vs individual rights)

# Zambia
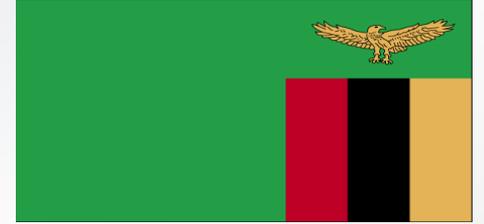
- CRPD ratification: 1/2/2010
- Focal point: Ministry of Community Development appointing focal point persons in relevant ministries
- Article 33(2) framework: **Independent Monitoring Unit** (IMU) – initiated by civil society, not CRPD compliant
- Article 33(3) – **Zambia Federation of the Disabled** (ZAFOD)

# Zambia
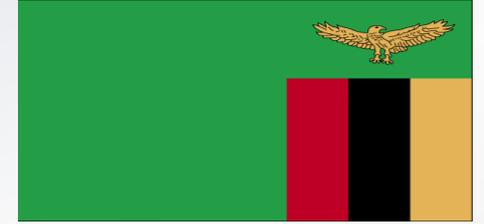
## Strengths:

- Civil society is actively engaged in the implementation and monitoring process of the CRPD

- DPOs understand CRPD provisions and follow ongoing legislative changes

- Using CRPD as an advocacy tool

- Planning advocacy in a strategic manner

- Awareness-raising in the community

## Challenges:

- Developing country – no internal funding for CRPD implementation

- Government did not provide funding for the established IMU

- Sustainability: funding from intl. donors ended in January 2013

- IMU lacked independent element – greater role for the Human Rights Commission

# Austria

- CRPD ratification: 26/09/2008
- Focal point + Coordination mechanism: **Ministry of Social Affairs**
- Article 33(2) framework: **Monitoring Committee**
- Article 33(3): **Austrian National Council of Persons with Disabilities** *(ÖAR)*

# Austria

**Strengths:**

- Monitoring committee is pluralistic (7 members: 4 DPO representatives, 1 from academia, 1 from human rights NGO, 1 from a development organisation)

- Implementing Article 33(3) through public meetings – participatory discussion (e.g. on inclusive education)

- Formal establishment of a new monitoring body, because the country did not have a Paris Principles compliant NHRI

# Austria

**Challenges:**

- Committee is only in charge of federal matters, the provinces ("*Länder*") are to determine their own monitoring mechanism

- Monitoring Committee is lacking resources

- Challenges to include persons with disabilities in monitoring the CRPD (and moreover in the implementation) in a systematic way

- Difficult to understand the cross-cutting nature of the CRPD

# 6. Criteria for meaningful NGO participation

- Formal structure for participation (Advisory Boards, Committees)
- Active and effective involvement of civil society (esp. DPOs)
- Commitment of the decision-makers through funding and transparency
- Participation from early-stage of legislative and policy process
- Active working relationship between stakeholders
- Broad collaboration, awareness raising at grass root level
- Continuous evaluation of the collaboration, capacity-building
- Direct influence by providing evidence-based information

# What is the situation in your country?

- The established Article 33 framework:

  ➢ Focal point(s):

  ➢ Coordination mechanism:

  ➢ Independent element:

  ➢ Involvement of civil society:


- Positive aspects?

- Challenges? Obstacles?

- The way to move forward?

# Conclusions and recommendations 1/2

- The full participation of persons with disabilities requires great structural changes and the elimination of past exclusive patterns – **shift from tokenistic consultation and meaningful involvement**

- Past working methods of the governments and NHRIs were highly inaccessible – developing **new, accessible and transparent working methods, reasonable accommodation**

- **Formal designation** of the framework

# Conclusions and recommendations 2/2

- Capacity building should be available including the most marginalized segments of the disability movement to engage in policy and decision-making processes – to **avoid a fragmented disability movement**

- Independent, long-term funding should be provided for members of the Article 33 framework to carry out systematic monitoring activities – to **achieve sustainability**

- The quality of participation of DPOs and the work of the Article 33 framework should be also regularly monitored to avoid illusive functioning – developing **indicators and benchmarks**

# Does Article 33 CRPD require a too abstract, or complicated monitoring mechanism?
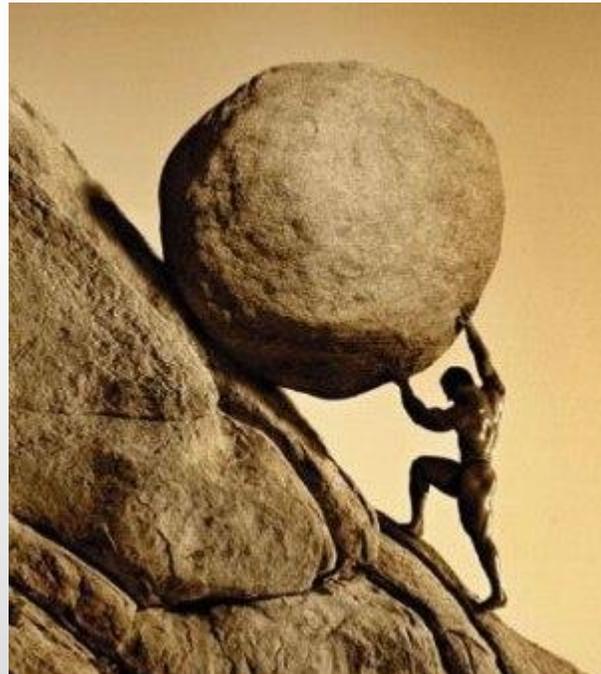
# Thank you for your attention!

**Get in touch!**

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# Disability assessment in the light of the UNCRPD

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

SEMINAR FOR NATIONAL CIVIL SERVANTS AND NGO STAFF

Alex.Cote

Triers, 13 october 2017

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# What is the role of the disability assessment?

- Granting a disability status (the disability card)
- Elgibility to a specific scheme only?
- Assessing support needs ?
- Orientation
- Curtailing rights – protection

## Disability assessment to justify to determine eligibility to support

- Disability status: "disability/inclusion" card?

- Access to social protection benefits and services?

- Insurance: in case of work related or other accident leading to impairment?

- Reasonable accommodation?

## To assess the "capacity" to exercise right (not in line with CRPD)

- "Mental capacity" assessment / functional test : could lead to deprivation of legal capacity, denial or right to decide for yourself, forced treatments…
- "IQ test" can lead to exclusion of children from mainstream or any form of education
- Work capacity assessment can contribute to further exclusion for labor market
- "Parenting" capacity in case of adoption..

## To which question does it answer?

- What is the person able to do?
- What is the person not able to do?
- What are the support needs of the person?
- What are the barriers faced by the person?
- What would it take for the person to function equally?
- What would it take for the person to participate equally?

**DISABILITY ASSESSMENT IN THE CONTEXT OF DISABILITY AND ELIGIBILITY DETERMINATION**

# Unbundling



# DISABILITY ASSESSEMENT



| IMPAIRMENT APPROACH | FUNCTIONAL APPROACH | + SUPPORT NEEDS | DISABILITY APPROACH |

Measuring the severity of health conditions and the impairments associated with them

Assessing functional limitations in basic activities, independent of environmental factors

Assessing support needs resulting from the interaction between intrinsic factors (health conditions, impairments, functional limitations) and environmental factors

COMMUNITY BASED ASSESSMENT

# DISABILITY DETERMINATION

- Is the person considered a person with disability, under the legal definition of the relevant regulations, schemes and policies?
  - For the purpose of this act disability is defined as…
  - Most often those definitions are actually criterias and tresholds set the enable eligibility determination, they are not per se a definition of persons with disabilities or disability.
- It can lead to attribution of an official disability status which might give access to benefits and/or be one of the criteria of eligibility among others to access benefits and services.

# ELIGIBILITY DETERMINATION

- It might include means test related criteria or others
- It is the ultimate decision level in the process


- Disability and Eligibility determination criteria can evolved independently from the disability assessment

## CRITICAL AND SENSITIVE BECAUSE

PERSONS WITH DISABILITIES

POLICY MAKERS

DISABLED PEOPLE ORGANISATION

ELIGIBILITY PROCESS

ELIGIBILITY PROCESS TARGETING AND RESOURCE ALLOCATION

ELIGIBILITY PROCESS ENSURING ACCESS TO SUPPORT FOR THEIR MEMBERS

ENTITLEMENTS SUPPORT SERVICES AND BENEFIT

MANAGE AVAILABLE RESOURCES

LONG TERM SUSTAINABILITY

ONE OF THE MAIN TOOL TO IMPACT GOVERNMENT REOSURCES ALLOCATIONS

## % of population recipient of disability benefits



MT EL PT FR CY ES IT AT DE RO LU EU PL NL BG HU UK LV BE SE HR SI SK LT CZ EE DK FI IE

Men    Women
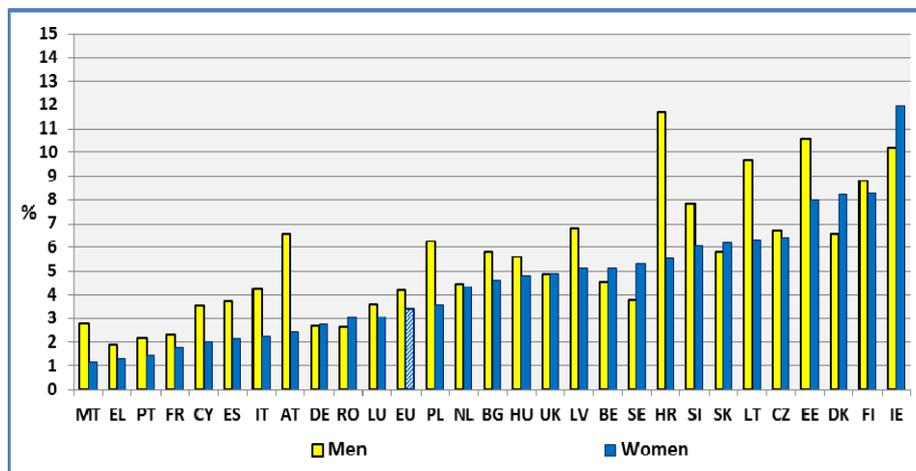
# Disability benefit as % of GDP in 2013

(Aned, 2017)
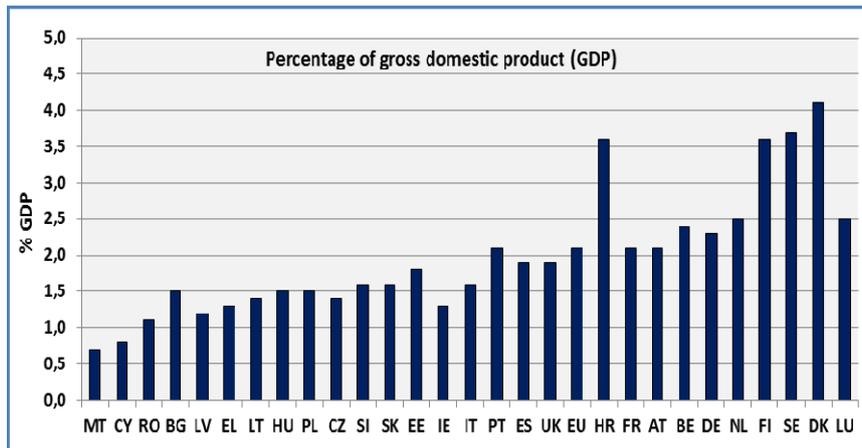


# Public spending on "Incapacity" over time

(OECD database)
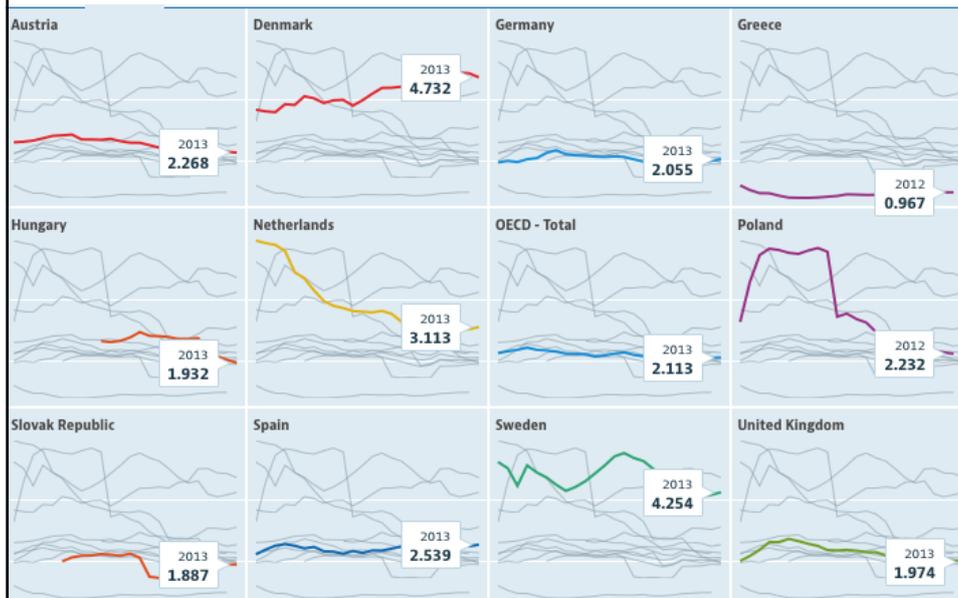
# The credibility issue <sub>(Bickenbach and al, 2015)</sub>

- Rising number of complaints and appeal against decision with significant overruling as a results:
  - USA: More than 38 percent of awards to individuals who applied for Disability Insurance between 1997 and 2000 were made after an initial denial
  - In the UK a total of 142 complaints against the PIP assessment process in 2015/16 against 1391 in 2016/17. 40-50% of the complaints are upheld.
  - 1,287,323 Employment & Support Allowance (Work capabilities assessment) appeals, at least 567,634 decision overturned in their favour.

# What DPOs are saying in EU about eligibility ... (Aned, 2017)

- Several country reports included criticisms of eligibility rules that effectively excluded some people with disability-related needs from financial and practical support, or created inequities by offering some groups preferential treatment. For example,
  - in Austria children and older people are excluded from receiving personal assistance as well as persons with intellectual, multiple or psychosocial disabilities.
  - Similarly in Croatia autistic people are not eligible for financial help for personal communication instruments.
  - Age discrimination was identified as a concern in Slovakia, Austria and the UK.
  - In the Germany report a concern was raised that eligibility/entitlement criteria are sometimes difficult to define (such as whether 'essential requirement' includes services and devices that support leisure activities) so that interpretations by caseworkers often lead to appeals in the case of rejected applications which are the case of stress and delay.

# … and assessment (ANED, 2017)

- Application and assessment procedures attracted a range of criticisms in a number of country reports. They were variously described as
    - time-consuming, frustrating, exhausting and humiliating, particularly for people with mental health problems or intellectual disabilities (Austria, Sweden and Germany),
    - too bureaucratic (Portugal, Latvia, the Netherlands),
    - inflexible (Iceland) and invasive of people's privacy (Sweden). T
    - he complexity of procedures was a concern in Germany and Slovakia.
    - A linked criticism was that procedures took too long (Croatia, Ireland, Latvia, Portugal, the Czech Republic and Sweden).
    - In some countries there was criticism of the basis on which decisions were made, ie reflecting a medical model of disability (Cyprus, Iceland) and about the type of staff making decisions (Cyprus, Finland).

- In the Netherlands the country report commented positively about the large discretionary freedom given to municipalities to support disabled people with cash benefits, supports, and devices. This allowed municipalities to tailor support to an assessment of individual circumstances.

# WHAT THE CRPD SAYS?

# Prescriptive or not?

- Preambule and art 1 insist on the **interaction** between **the persons with an impairment** and **barriers in the environment** hindering **participation**

- Art 26: mentioned multidisciplinary assessment of individual **needs and strengths** for habilitation and rehabilitation

- Art 12 mention a **review of support** provided to exercise legal capacity.

# Elements of the CRPD committee jurisprudence

- Czeck Republic
  - The Committee calls upon the State party to amend the definitions of disability and persons with disabilities in its legislation and to make explicit reference to the barriers faced by persons with disabilities in the above-mentioned definitions, in order to harmonize them with the definitions in the Convention.
- Portugal
  - The Committee recommends that the State party review the assessment criteria to determine the degree of disability of the individual to bring them into line with the Convention, and adopts suitable regulations in its legislation and policies. The Committee also recommends that the State party ensures that all persons with disabilities are able to secure their disability certificate, and that access to social protection programmes and aid is available to all persons with disabilities.
- Serbia
  - The Committee recommends that the State party review its legislation, including assessment of disability and support schemes, and harmonize it with the Convention, including the human rights model of disability. (…) It further recommends the State party to review the assessment of working capacity to eliminate the medicalised approach and to promote the inclusion of persons with disabilities in the open labour market.
- Slovakia
  - The Committee recommends that the State party adopt a human rights-based definition of disability in the regulations relating to the assessment of disability.

# Elements of the CRPD committee jurisprudence

- Korea:
  - The Committee recommends that the State party review the current disability determination and rating system under the Welfare of Disabled Persons Act to ensure that the assessment reflects the characteristics, circumstances and needs of persons with disabilities(…)
- Sweden
  - it is also concerned about families with disabilities being subjected to additional investigations, carried out by local authorities and social services in the framework of the national adoption system, to assess their parenting ability.
  - 46. The Committee recommends that the State party ensure the prohibition of discrimination on the basis of disability in adoption procedures.
- Croatia
  - It further recommends that benefits aiming at alleviating increased costs arising from disability should be based on an assessment of the individual's support needs, and should disregard any financial assets test.
- Bolivia
  - The Committee recommends that the State party amend the criteria for certification of disability to reflect the social, human rights-based model of disability, and that it make the procedure accessible, simple and free of charge for all persons with disabilities.

# General comment art 19

- The assessment should be based on a human rights approach to disability, focus on the requirements of the person because of barriers within society rather than the impairment, take into account, and follow a person's will and preferences, and ensure the full involvement of persons with disabilities in the decision-making process.
- Support for persons with disabilities should be assessed, through a personalised approach, and tailored to the specific activities and actual barriers that persons with disabilities face in being included in the community.
- The assessment should acknowledge that persons with disabilities require access to participate in activities that are varying over time.

**WHICH SCENARIOS?**

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Needs/rights driven ? = waiting list and pressure on policy maker + creation of new services

NEEDS / RIGHTS

OFFER / SUPPLY

Public Resources
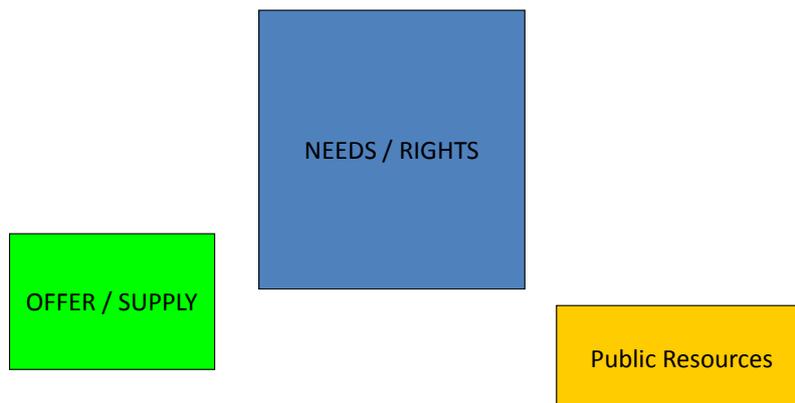
Supply driven? = waiting list but biaised assesment as there is a lack of diversity

OFFER / SUPPLY

NEEDS / RIGHTS

Public Resources

Resources driven: the fake perfect match?= no waiting list as state entitle as much as it can afford

NEEDS / RIGHTS

OFFER / SUPPLY

Public Resources

"ONE STOP SHOP"

Individuals With disabilities

ELIGIBILITY DETRMINATION



Not "ONE STOP SHOP"

Individuals With disabilities

ELIGIBILITY DETERMINATION

ELIGIBILITY DETERMINATION

ELIGIBILITY DETERMINATION
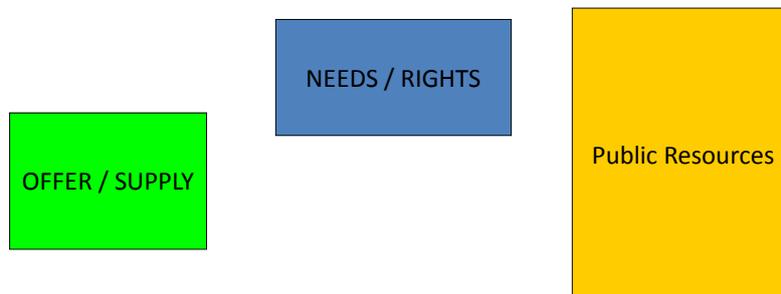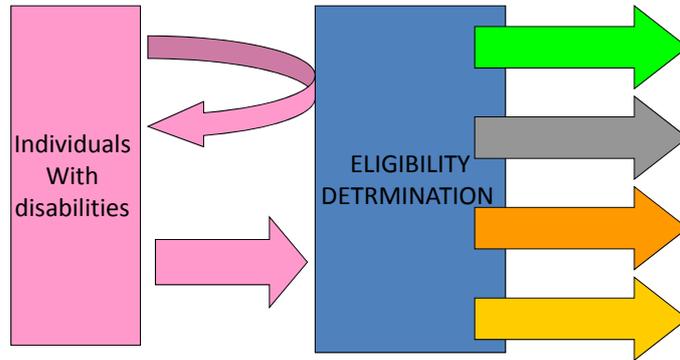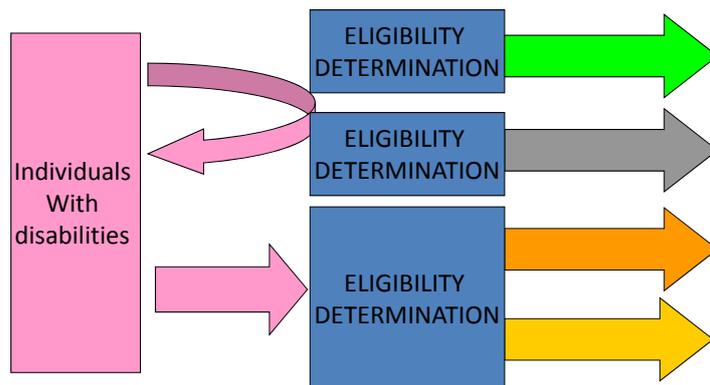
# What is assessed?
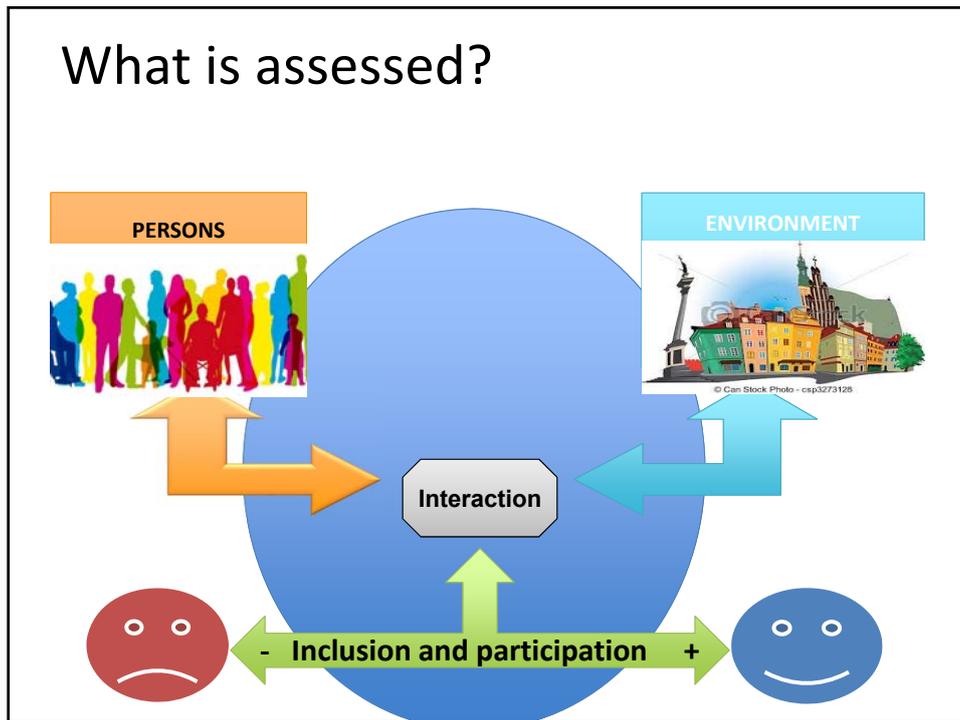


The incapacity, capacity, support requirements?

- The person can't…
- The person can…
- The person can only if ….
- In absolute
- In his/her environment ?

## Different scenarios

| | | | |
|---|---|---|---|
| Medical Assessment | | | |
| Medical Assessment | Functional Assessment | Needs assessment | |
| Medical Assessment | Overall Assessment | | |
| Medical Assessment | Functional Assessment | Needs assessment | Social assessment |
| Medical Assessment | Social assessment | | |

DISABILITY AND ELIGIBILITY DETERMINATION

Financial assistance

Access to services
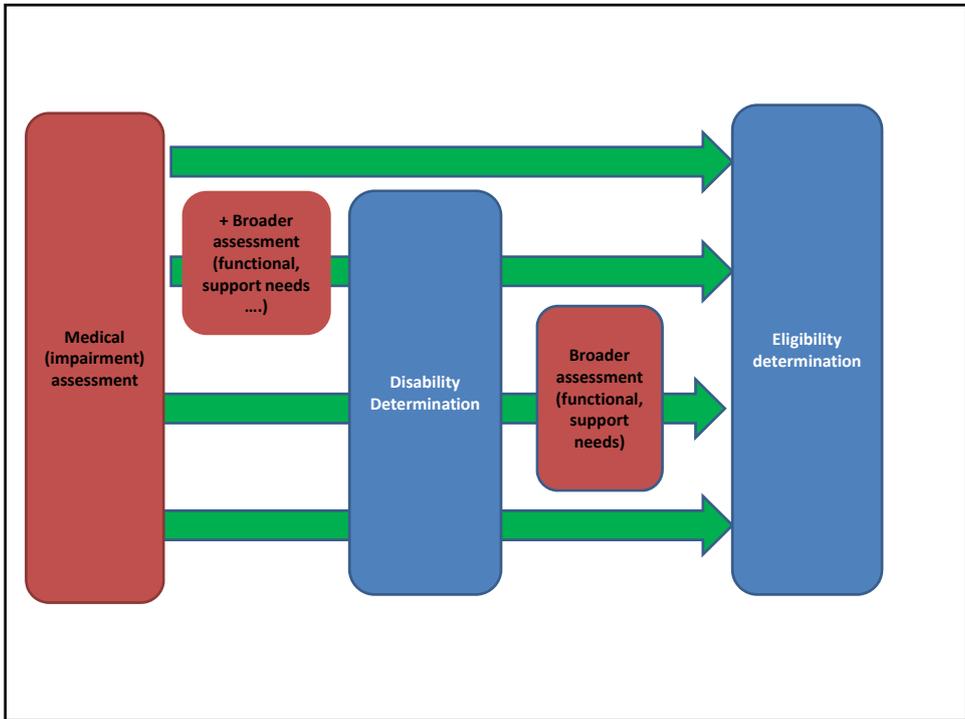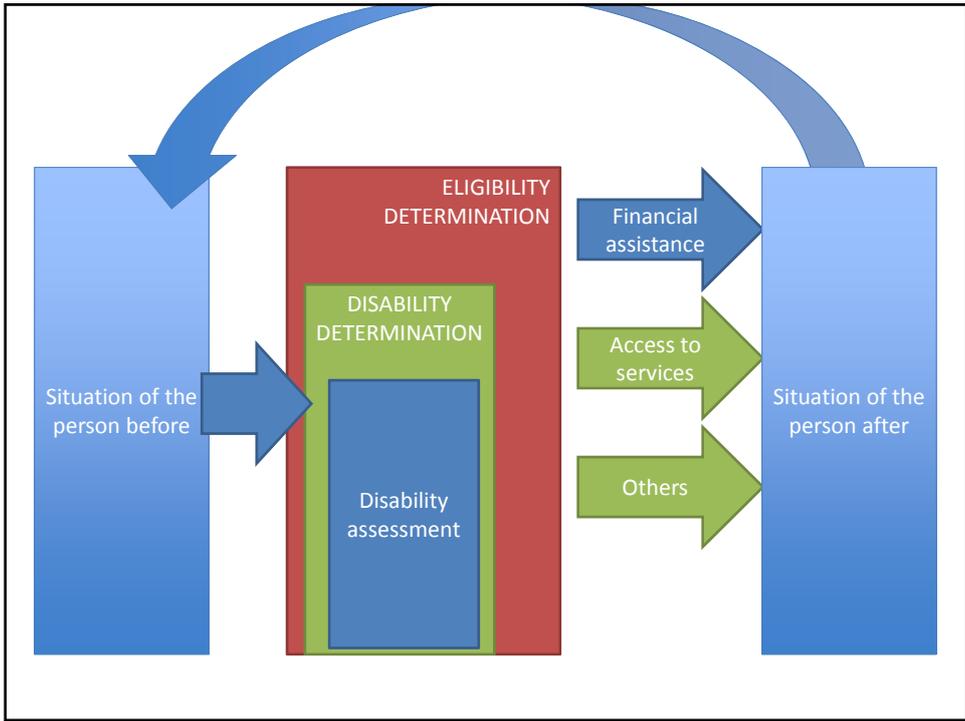
Others
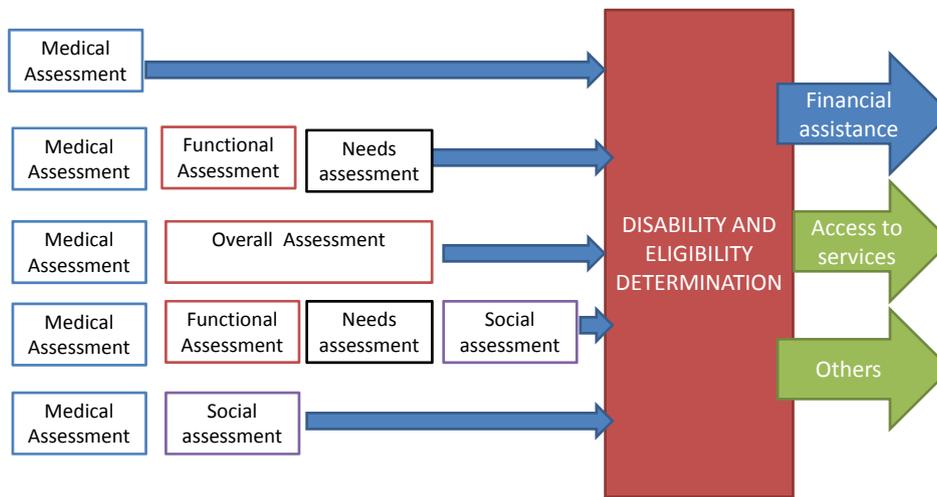
## Assessment is always a (very) partial description of reality

Experience of disability

# Which Disability Assessment?

| IMPAIRMENT APPROACH | FUNCTIONAL APPROACH | + SUPPORT NEEDS | DISABILITY APPROACH |
|---|---|---|---|
| Measuring the severity of health conditions and the impairments associated with them | Assessing functional limitations in basic activities, independent of environmental factors | | Assessing support needs resulting from the interaction between intrinsic factors (health conditions, impairments, functional limitations) and environmental factors |

COMMUNITY BASED ASSESSMENT

# What is assessed? (Bickenbach, 2017)

| Approach | Conception of 'disability' | Standardize tool or guideline | Criteria |
|---|---|---|---|
| IMPAIRMENT | Medical<br><br>Health state (injury, disease or syndrome), Plus problems with body functions and structures | Impairment guidelines:<br><br>*AMA Guidelines for the Evaluation of Permanent Impairments* (6th ed.) | 'Baremas' criteria:<br><br>Presence of problem at the body level as indirect indicator of 'whole person' or disability rating |
| FUNCTIONAL | Functional<br><br>Problems or limitations in basic activities | Functional Capacity Evaluations (FCE):<br><br>*Functional Status Questionnaire Disability Assessment Structured Interview Work Ability Index, etc.* | ADL/IADL criteria:<br><br>Presence of a problem or limitation in basic activity as indirect indicator of disability rating |
| DISABILTY | Disability<br><br>Disability is the outcome of an interaction of health condition and environmental factors at the body, person and societal levels | Disability Assessment:<br><br>WHODAS2[lvii]<br>ICF Checklist[lviii]<br>ICF Core Sets[lix] | Bio-psycho-social criteria:<br><br>Description of kind and severity of disability as an outcome of interaction between an individual's health and functional capacity and environmental factors |

# Further data collection

- Are the data collected for disability and eligibility determination used for policy planning and monitoring.

  - What are the support needs of people?
  - Who is currently accessing support? Assistive devices?
  - What is the challenges faced by children, women, adult, and elderly people?
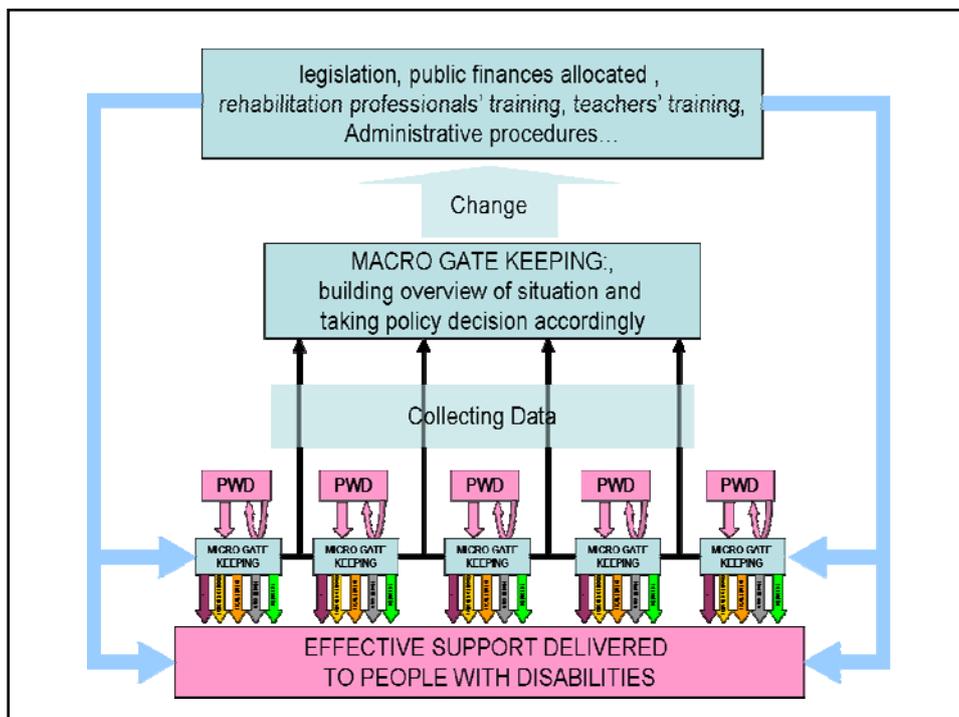
# Issues to consider

Unbundling
- Benefits
- Eligibility criteria
- Disability determination
- Disability assessment

# Issues …

Legal
- What is the legal definition of disability related to the determination and assessment?
-  Which legal framework govern the assessment
- Appeal possibilities?

Technical:
- What is the classification used ?
- Who are the staff involved / needed for the assessment?
- Information system

Access
- How easy is the process? Availability, accessibility, affordability, quality

# Issues…

Political stakes
- For DPOs :
  - accessing support and
  - controlling the sharing of resources
- For professional and institutions:
  - resistance to change, loss and gains…
- For government
  - delivering support and
  - controlling expenditures
  - Avoiding fraud..

# CRPD compliant disability assessment

- An assessment that is CRPD-compliant should respect the following principles:
  - Respecting the dignity of the person
  - Full accessibility (information, meetings, etc..)
  - Having been designed with the participation of representative DPOs
  - Country-wide coverage (proactive outreach strategy) and particular attention to those most in disadvantage (rural, remote, etc..)
  - Respecting the diversity of disability
  - Respect for privacy (of data)
  - Gender-sensitive and respectful of indigenous people
- Ramp to access rights versus gatekeeping which sends a negative message
- Making disability assessment processes CRPD compliant is part of the obligations of States Parties

# Assessing the procedure with CRPD

| |
|---|
| Art.5 Is the assessment procedure non discriminatory on the basis of disability, sex, sexual orientation, religious or ethnic origin? |
| Art.5 Is there sufficient guarantee for reasonable accommodation in the assessment procedure? |
| Art.6 Does the procedure respect the autonomy and dignity of women and girls with disabilities? |
| Art.7 Is the procedure adapted to the specific needs of the child ? Does the assessment procedure allow the child to express his or her opinion? |
| Art. 9 Is the disability determination procedure accessible to any person with a disability (physical, information, communication, etc.)? |
| Art. 12 Does the disability determination procedure support the exercise of legal capacity? |
| Art. 21 Can the person with disability consult his / her file to exercise his right to freedom of expression and opinion by accessing understandable information and using his/her preferred means of communication? |
| Art.22 Does the procedure guarantee the protection of privacy and the confidentiality of information? |
| Art. 31 Are the privacy and confidentiality of the collection of private data (use of individual files, etc.) guaranteed? |

# SOME CONSENSUS IN A COMPLEX QUESTION..

# Some element of consensus…

- Disability determination
  - Should be CRPD compliant
  - is not disability prevalence
  - Should not be use to curtail rights
  - Should not contribute to prejudice
  - Is not required for protection against discrimination
  - Include assessment of support requirement
  - Should have appeal procedure
  - Should be simple enough for clarity and transparency purpose

# Bibliography

- ANED Social protection for disabled people in Europe: Synthesis report R Sainsbury, A Lawson and M Priestley (ANED)`2017
- Arnould Carlyne, Barral, Bouffioul, Castelein, Chiriacescu, Cote, 2012, Disability Assessment Mechanisms : Challenges and Issues at Stakes for the Development of Social Policies in light of the United Nations Convention for the Rights of Persons with Disabilities
- Bickenbach; Posarac; Cieza; Kostanjsek,. 2015. Assessing disability in working age population : a paradigm shift from impairment and functional limitation to the disability approach. Washington, D.C. : World Bank Group.
- CRPD Committee concluding recommendations and general comment 6 on article 19
- OECD database

International
Labour
Organization

# Employment of persons with disabilities: EU disability law and UN CRPD
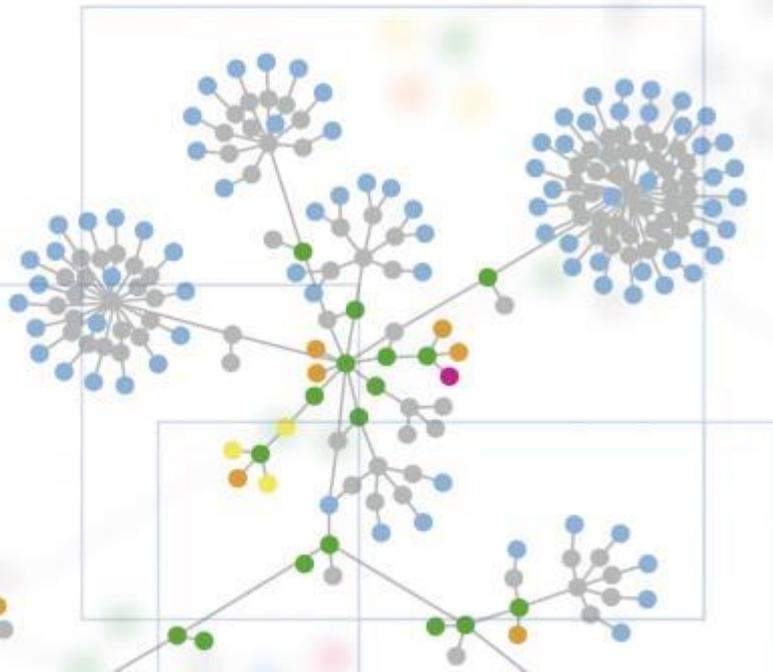
Stefan Trömel
13 November 2017

# Evidence of Inequality
## (OECD - 27 countries*)

Employment situation of working age persons with disabilities:
- 44% are employed
- 14% registered unemployed
- 49% economically inactive
- Employment rate falling in many OECD countries
- Employment rate of people with mental health disabilities – especially low
- More likely to be in part-time, low-paid work

Comparable figures for non-disabled persons
- 75% employed
- 7% are registered unemployed
- 20% economically inactive

*Organization for Economic Cooperation and Development (2010).  Sickness, Disability and Work: Breaking the Barriers. Accessed at https://en.wikipedia.org/wiki/Organisation_for_Economic_Co-operation_and_Development.

# EU Directive 2000/78 on equal treatment in the workplace

- Covers religion or belief, disability, age and sexual orientation
- Concept of discrimination covers direct and indirec discrimination, harassment, instruction to discriminate
- Scope (private and public sector): Access to employment and self-employment, vocational training, employment and working conditions, membership in organizations of workers and employers
- Specific article on reasonable accommodation for disabled persons
- Allows for positive action
- Reversal of the burden of proof

# Work and Employment – new policy approach

- ## UN CRPD Article 27:

  - States Parties recognize the right of persons with disabilities, to work on an equal basis with others

    - Right to opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible

  - Based on Universal Declaration of Human Rights Art 23 and the International Covenant on Economic, Social and Cultural Rights, Art 6

# UNCRPD Article 27
# Work and Employment

- States Parties shall safeguard and promote realization of the right to work by taking steps to:
    - Prohibit discrimination in all aspects and forms of employment
    - Protect the right, on equal basis, to just and favourable conditions of work on equal basis with others
    - Ensure exercise of trade union rights on equal basis with others
    - Promote employment opportunities and career advancement in the labour market, as well assistance in finding, obtaining, maintaining and returning to employment
    - Promote opportunities for self-employment, entrepreneurship
    - Employ persons with disabilities in public sector
    - Promote employment in the private sector
    - Ensure reasonable accommodation is provided in workplace

# Denial of reasonable accommodation as a form of discrimination

➢ How to apply disproportionate or undue burden

➢ The need to provide technical assistance

➢ Provision of financial assistance for those accommodations that have a cost

➢ Reasonable accommodation in the context of mental health conditions: disclosure and confidentiality

# ILO tools for employers



- **"Promoting diversity and inclusion through workplace adjustments: A practical guide"** (EN, FR, ES)



- **Joint ILO/UN Global Compact "Guide for business on the rights of persons with disabilities"** also available as easy-to-read version
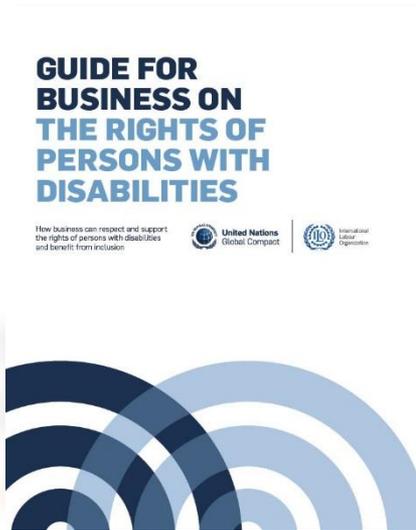
# Affirmative action measures

- Quota systems
  - Public and private sector
  - Quota/levy system
  - Pros and cons of quota
  - Requires disability certification system
- Public procurement
  - Examples from South Africa and US
- The need for self-identification

# Inclusive training and employment services

- Disability inclusion in vocational training, including apprenticeship schemes and other youth employment initiatives

- Disability-inclusive public employment services which can be complemented with targeted services

- Disability management/return to work services
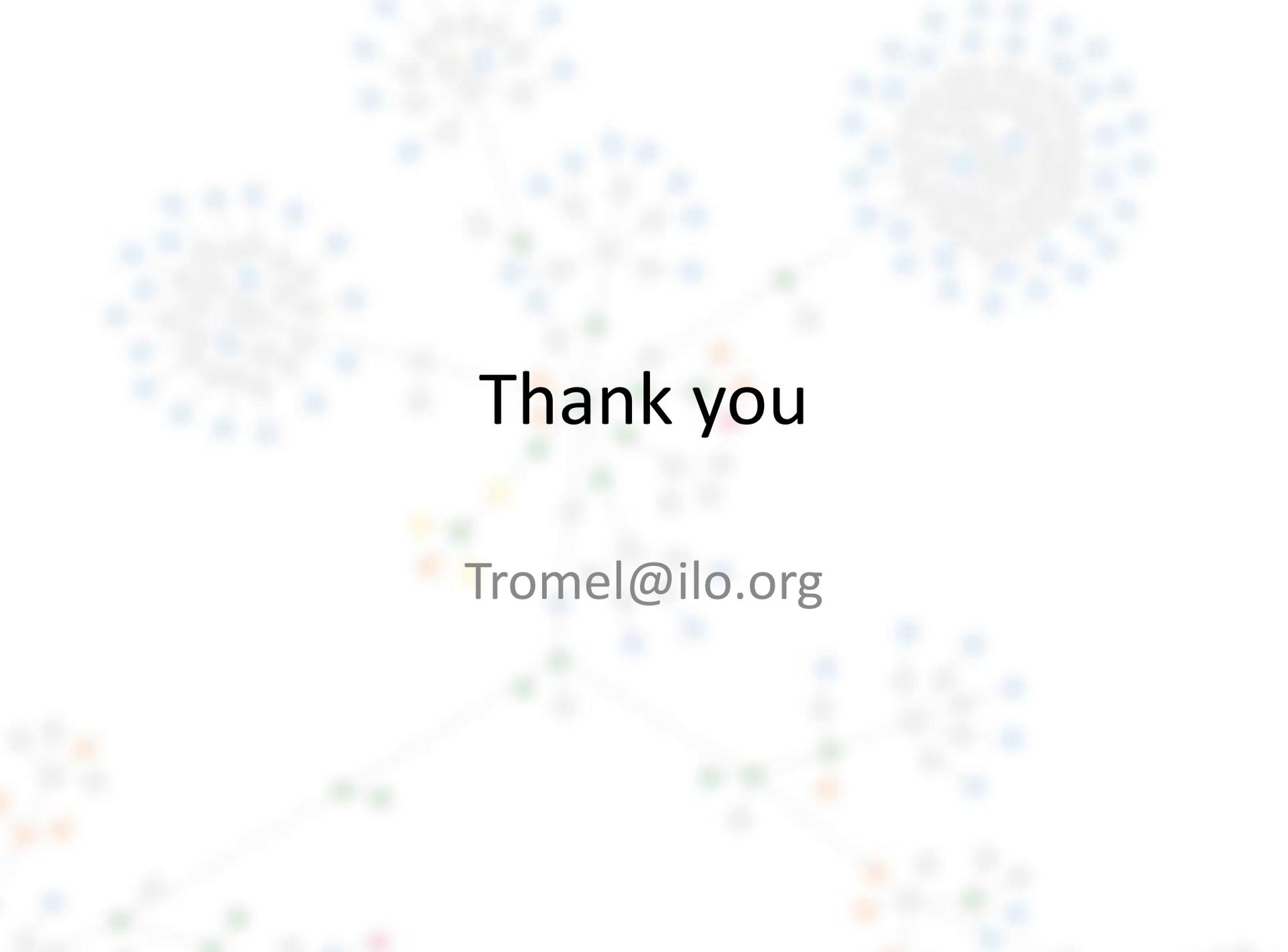
# Thank you

Tromel@ilo.org

# Accessibility Legislation in Europe

Susanna Laurin, Funka

# Relevant assignments

- Mandate 376
- SMART monitoring study
- WADex
- ETSI Special Task Force
- COST Network
- IAAP Europe
- IAAP Nordic chapter

**Funka**

# Funka

- Founded by Swedish disability organisations
- Private company 2000
- Oslo 2010
- Madrid 2013

**IAAP** International Association of Accessibility Professionals

Funka

# What we do

- Consulting
  - Development
  - Analysis, test and advice
  - Training
- Research and innovation
- Government assignments
- Collaboration projects
- Standardization

Funka
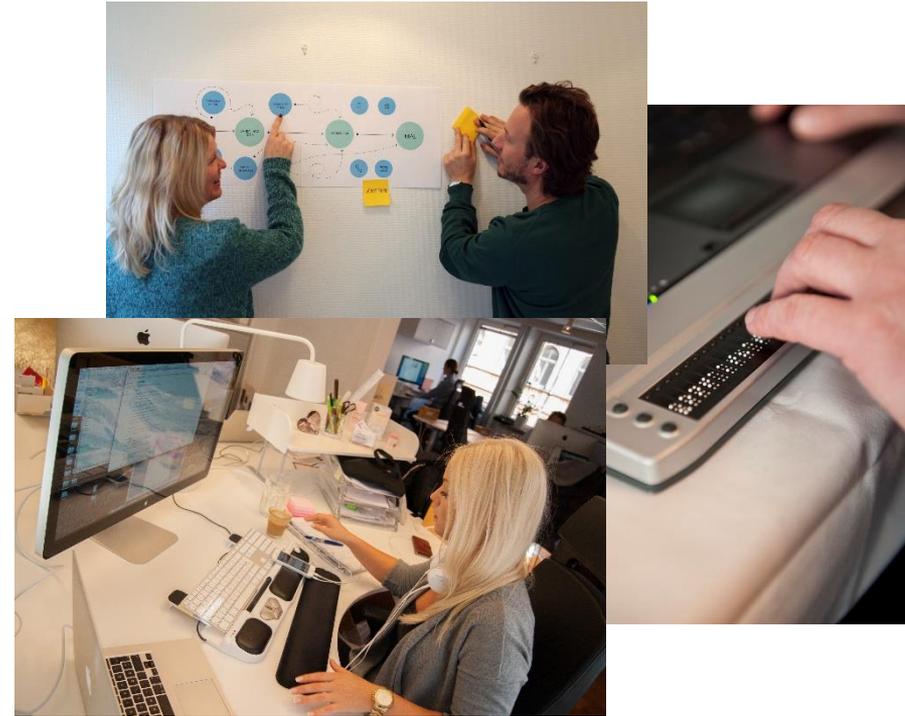
# From recommendation to legislation



## The current situation

- UNCRPD
- National discrimination acts
- Policy work
- Employment laws
- Procurement regulations
- Few laws on web accessibility

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# The current situation

- UNCRPD
- National discrimination acts
- Policy work
- Employment laws
- Procurement regulations
- Few laws on web accessibility

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In Europe, the carrot sometimes beats the stick

# The general perception

Without law

With law

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# But in reality

No law

General law

Detailed law



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# How on earth … ?

Cultural difference

Well implemented policies

Not too precise regulations

Active end user organisations

Competent Industry

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But things are changing

# The Procurement Directive

Until 2016

When possible,
the specifications SHOULD be
decided taking accessibility criteria
for persons with disabilities in
account.

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From 2017

When the procured is going to be used by humans, the technical specifications SHALL be decided taking all users needs into account, including persons with disabilities.

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# Who, how and when

- Public sector (and beyond)
- Above the threshold
- National implementation
- January 1, 2017

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# What does it cover

- ICT in general
- EN 301 549
- WCAG 2.0 level AA
- Minimum requirements



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Procurement can make a difference!

# How?

- Support for procurers
- Equal oportunities for suppliers
- Knowledge will spread
- We already see the trend

Funka
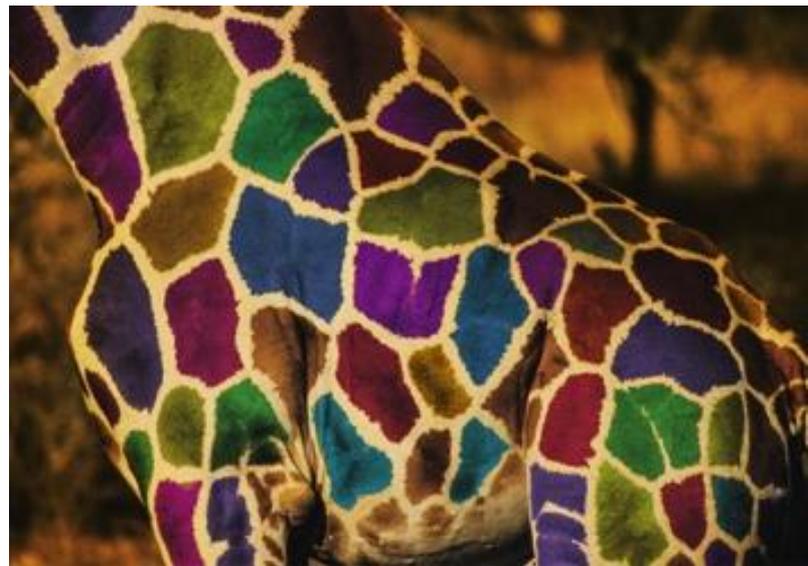
# EN 301 549:
# Accessibility requirements for procurement of ICT products and services in Europe

ICT what?

# A broad standard

- Built environment requirements
  - Placement
  - The way to the machine
  - Pick number 5
  - Height
- Software requirements
  - Text size
  - Text to speech
  - WCAG

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# A complex standard

- Functional performance statements
- Technical requirements



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Not perfect, but …
the best we have!

# Help and support

- Tool kit
- Translations
- Videos
- Training

**Funka**

And it is used around the world

# Directive of the European Parliament and of the Council on the accessibility of public sector bodies' websites

# Who are affected?

- Public sector
- Serving the general interest
- National decisions



Funka
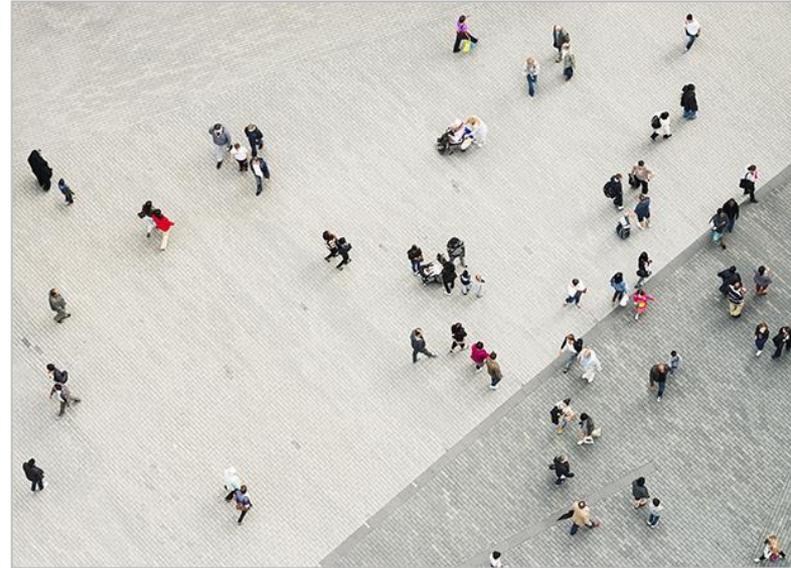
# Out of scope

- Broadcasters
- NGOs
- Private sector



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# What is covered

- External web site
- Intranet
- Extranet
- Documents
- Apps
- EN 301 549 (WCAG 2.0 AA)
- Minimum requirements

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# Exceptions

- Archives and old material
- Old pre-recorded media
- Live media
- Maps (if alternatives exist)
- Heritage collections
- User driven content
- Content for closed groups



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# How will this happen?

- National implementation
- National monitoring
- European Commission decides on the method
- Accessibility statement
- Complaints mechanism



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We are in transposition

# Transposition topics at national level

- Who should be covered?

- What content should be covered?

- What should be required beyond EN 301 549?

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# Stepwise entering into force

- Sept 23, 2018: national implementation
- Sept 23, 2019: new websites
- Sept 23, 2020: existing websites
- June 23, 2021: apps



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**PROPOSAL:**
**European Accessibility Act**

# In a perfect world this will happen

- Procurers set requirements
- Suppliers meet the requirements
- Website owners are being controlled
- Results are made public
- End users complain

**Funka**

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

## Statistics and data collection about persons with disabilities

Elena De Palma

depalma@istat.it

ERA seminar, Trier 14 November 2017

# Increased need of disability data

- The International Year of Disabled Persons (1981)
- The World Programme of Action concerning Disabled Persons (1982)
- The United Nations Decade of Disabled Persons (1983-1992)
- The Standard Rules on the Equalization of Opportunities for persons with disabilities (1993)
- UN Convention on the Rights of the Child  (1989)
- UN Convention on the Rights of Persons with Disabilities (2006)
- Sustainable Development Goals (SDGs) (2015)

# UNCRPD Article 31 – Statistics and data collection

☐ States Parties undertake to **collect appropriate information**, including statistical and research data, **to enable them to formulate and implement policies** to give effect to the present Convention.

☐ **The information collected** in accordance with this article **shall be disaggregated,** as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

☐ States Parties shall assume r**esponsibility for the dissemination** of these statistics and ensure their **accessibility** to persons with disabilities and others.

# Why do we need data on disability?(1)

➢ **Raise awareness:** consistent data helps bring attention to this population by demonstrating the extent and impact of disability

➢ **Empower advocates**: accurate information can provide strong support for advocacy efforts because it helps justify the need for change and for expenditure of scarce resources.

➢ **Identify gaps:** reliable data can identify gaps in services that either civil society or government needs to address.

# Why do we need data on disability? (2)

➢ **Prioritize interventions:** data can provide decision-makers with basic information that can be used to determine priorities in policies, programs and services for persons with disabilities and their families.

➢ **Monitor outcomes:** Collecting consistent data elements over time can be used to monitor outcomes. This allows policy makers to expand effective programs and eliminate or modify ineffective ones.

➢ **Monitor progress** on the implementation of the UNCRPD, UNCRC and SDGs. Data can be used to compare levels of participation between those with disabilities and those without – and thereby assess equitable access to opportunities.

# Way to collect disability data (1)

Three main types of national data collection systems:

➢ Population census

➢ Sample Surveys

➢ Administrative data

# Way to collect disability data (2)

**Population Census:**

✓ has the advantage of providing complete population coverage,

       BUT

✓ space and time constraints make difficult to collect accurate information about disability as only few questions or even one question can be usually added on disability.

Census data should be readily used, where available, to develop more detailed follow-up surveys.

# Way to collect disability data (3)

**Sample surveys** are designed to be administered to a sub-set of population in order to estimate population attributes.

PwD are a relatively small population, so obtaining a sufficient (representative) sample can be very costly.

A sample survey cannot provide detailed information for small geographical areas.

✓ A sample survey focused on disability

✓ Add short set of questions to identify PwD

✓ A disability module added to an existing survey

# Way to collect disability data (4)

**Disability surveys**

- ✓ maximise the amount of information that can be collected to meet users' needs.

- ✓ good sources of information about prevalence rates, causes and types of disability, underlying health conditions, severity and duration of disability, use of and need for assistive devices, changes in environment, policies and public awareness on disability.

Many countries do not conduct disability surveys because they are more costly than simply adding a few questions into a census or already existing sample surveys.

# Way to collect disability data (5)

**Disability module**

In many countries, national household surveys – covering topics such as health, education, living conditions, labour force, time use …  – are conducted on a regular basis.

These surveys try to identify short and long-term social trends.

Adding disability questions or a '**disability module'** to one or several of these surveys is a  cost-efficient and effective way of collecting disability data.

# Way to collect disability data (6)

**Administrative collections and registers** are composed of data that is collected as part of the normal operation of some service or programme, specific or not for PdW.

- ✓ provide useful information on the characteristics of people accessing disability services as well as details about the services provided (type, quantity, cost).

- ✓ cannot provide information about persons with disabilities who *need a service* or programme *but do not receive it.*

- ✓ are not good sources for estimating overall disability prevalence.

# Data on disability varies widely across the world due to:

1. different priority given to *disability* in the political agenda at national level

2. different level of local resources available for data collection at national level

3. cultural factors (such as differences in values and attitudes towards individuals with disabilities) influence reporting disability in the surveys

4. lack of a standardized approach to data collection (such as definition of disability, purpose of measurement, data collection method …)

The result is: No international comparability

# Eurostat data sources on disability

- European Health Interview Survey (EHIS)

- Statistics on Income and Living Conditions (SILC)

- other specific modules and surveys have been undertaken to collect disability related data:
  - ✓ Labour Force Survey (ad hoc module on employment of persons with disabilities (2002 & 2011)
  - ✓ European Health and Social Integration Survey (EHSIS, 2012)

- The European System of Integrated Social Protection Statistics (ESSPROS): disability benefits and disability pensions.

# Eurostat: sample surveys tools (a)

- One-question instrument: Global Activity Limitation Indicator (GALI) that is part of the **MEHM**

*For at least the past 6 months, to what extent have you been limited because of a health problem in activities people usually do?*

Would you say you have been:
- Severely limited
- Limited but not severely
- Not limited at all?

# Eurostat: sample survey tools (b)

- Multiple-questions instruments:
  - ✓ Activities of Daily Living (ADL)*
  - ✓ Instrumental Activities of Daily Living (IADL)**

*Personal care: Feeding yourself; Getting in and out of a bed or chair; Dressing and undressing; Using toilets; Bathing or showering.

** Household care: Preparing meals, Using the telephone, Shopping, Managing medication, Light housework, Occasional heavy housework, Taking care of finances and everyday administrative tasks.

# EU Statistics on Income and Living Conditions

☐ Annual survey that includes GALI.

☐ Eurostat annually publishes tables corresponding to the main SILC indicators (risk of poverty or social exclusion, material deprivation) using the GALI as a proxy to monitor the situation of disabled people.

☐ EU-SILC data is also used by ANED to produce estimations of the Europe 2020 indicators on employment and education in relation to persons with disabilities.

# European Health Interview Survey (EHIS)

- The **European Health Interview Survey**, which collects data every 6 years on the level of functioning and activity limitations in the population, health status, health determinants and healthcare use.

- It includes MEHM; difficulties in basic actions (seeing, hearing, walking…); difficulties in more complex activities (ADL; IADL)

# Labour Force Survey with *ad hoc* module (2002 & 2011)

**LSF:** Continuous sample survey providing quarterly results on labour participation of people aged 15 and over as well as on persons outside the labour force.

Ad hoc module:  Health problems and difficulties in basic activities

- Limitations in work caused by health problems/difficulties in basic activities (i.e. limitations in amount of work, in type of work, getting to/from work)
- Special assistance needed or used by people with health problems/difficulties in basic activities
- Limitations in work because of other reasons (personal/environmental)

# European Health and Social Integration Survey

☐ The 2012/2013 **European Health and Social Integration Survey**, the most comprehensive EU source of data on the barriers to participation for people having a health problem or a basic activity difficulty, covering a wide range of socio-economic, health and participation aspects

# European Health and Social Integration Survey

- Questions about general health and longstanding health problems (Minimum European Health Module, impairments, Activities of Daily Living - ADL, Instrumental Activities of Daily Living - IADL)

- Questions on barriers in 10 life domains:

| | |
|---|---|
| ☐ Mobility | Internet use |
| ☐ Transport | Social contact and support |
| ☐ Accessibility to buildings | Leisure pursuits |
| ☐ Education and training | Economic life |
| ☐ Employment | Attitudes and Behaviour |

# Eurostat sample surveys

- **EU-SILC:** global question on activity limitations (GALI)

- **EHIS:** limitation in basic activities (walking, seeing etc.) and more complex activities (ADL and IADL)

- **LFS AHM:** work related disability (specifically looking at limitations in amount, type, travel to and from work)

- **EHSIS –** barriers to life opportunities faced by people with health problems and impairments

Disability statistics is an online Eurostat publication presenting recent statistics on the situation of people with disabilities in the European Union (EU).

# Eurostat future strategies in progress

➢ 2017 **SILC** module on children includes a GALI variable adapted for children; Health module every 3 years

➢ **Global Activity Limitation Indicator** (GALI) as a 'core' social variable in all relevant surveys

➢ disability variables into the **Labour Force Survey** once every two years, thus creating a reliable monitoring tool on the employment of people with disabilities.

➢ investigates the possibility to introduce a **child module into EHIS** survey

# Data dissemination

☐ Disability statistics is an
online Eurostat publication presenting
recent statistics on the situation of people
with disabilities in the European Union (EU).

dati.disabilitaincifre.it/dawinciMD.jsp?p=hm&l=1

App   Importati da IE   Zimbra: In arrivo (10)   Istar MD   Glossario - Login   SAES - gestione corsi   Thematic glossaries -   IAEG-SDGs — SDG In   inIstat   Q-Bank - QUEST - Ho   »   Altri Preferiti

# DisabilitàinCifre

## http://dati.disabilitaincifre.it/

**Istat**   Ministero del Lavoro e delle Politiche Sociali

| Home | Data access | Documents and Glossary | Links | UNCRPD indicators | | Italiano | English |

This website disseminates official statistics on disability produced by Istat and institutions belonging to the National Statistical System. The available data have been processed and organized by Istat in the information system with the aim of documenting the living conditions and the level of social inclusion of people with disabilities and to provide support for the planning of the policies and monitoring of the UN Convention. Therefore, the information system has as privileged users the policy makers, the scientific community and, more generally, the stakeholders in the sector.

This website is one of the products of a broader project , currently funded by the Ministry of Labour and Social Policy , with the aim to increase statistical information on disability, in compliance with article no. 41 - bis of the National Law no. 162/98 and of the article no. 31 of the UN Convention on the Rights of Persons with Disabilities.

The indicators presented in the information system utilise different official data sources, statistical and administrative. The definitions of disability, on the basis of which were produced indicators, differ according to the source considered, for this reason particular attention has been paid to the development of a metadata system that provides vital information to the correct reading of the data.

The website is organized into 3 main sections: Data access, Documents and Glossary, and finally UNCRPD Indicators. It also provides a support area with links to national and international organizations relevant to the topics covered in the information system.

The Data access section allows the user to browse, query and download the available data.
The Documents and Glossary section provides pubblications, background information and clarification of terminology.
The UNCRPD Indicators section contains key indicators products for monitoring the UN Convention on the Rights of Persons with Disabilities

Contacts: cont@ctcentre
For statistical data and Istat pubblications - ph. +39 06 4673.3102-3-4-6

Privacy (External link) - Legal notice (External link)

**Istat - Istituto nazionale di statistica**
Via Cesare Balbo 16 00184 - Roma tel. +39 06 46731

# Monitoring the UN CRPD

Disaggregation requirements

- Need a straightforward and simple way to <u>identify persons with disabilities</u>

- Need <u>indicator/outcome data</u> (education, employment, income, health care access) from data collections (census/surveys) that also include the disability identifier.

# The ICF Model - 2001
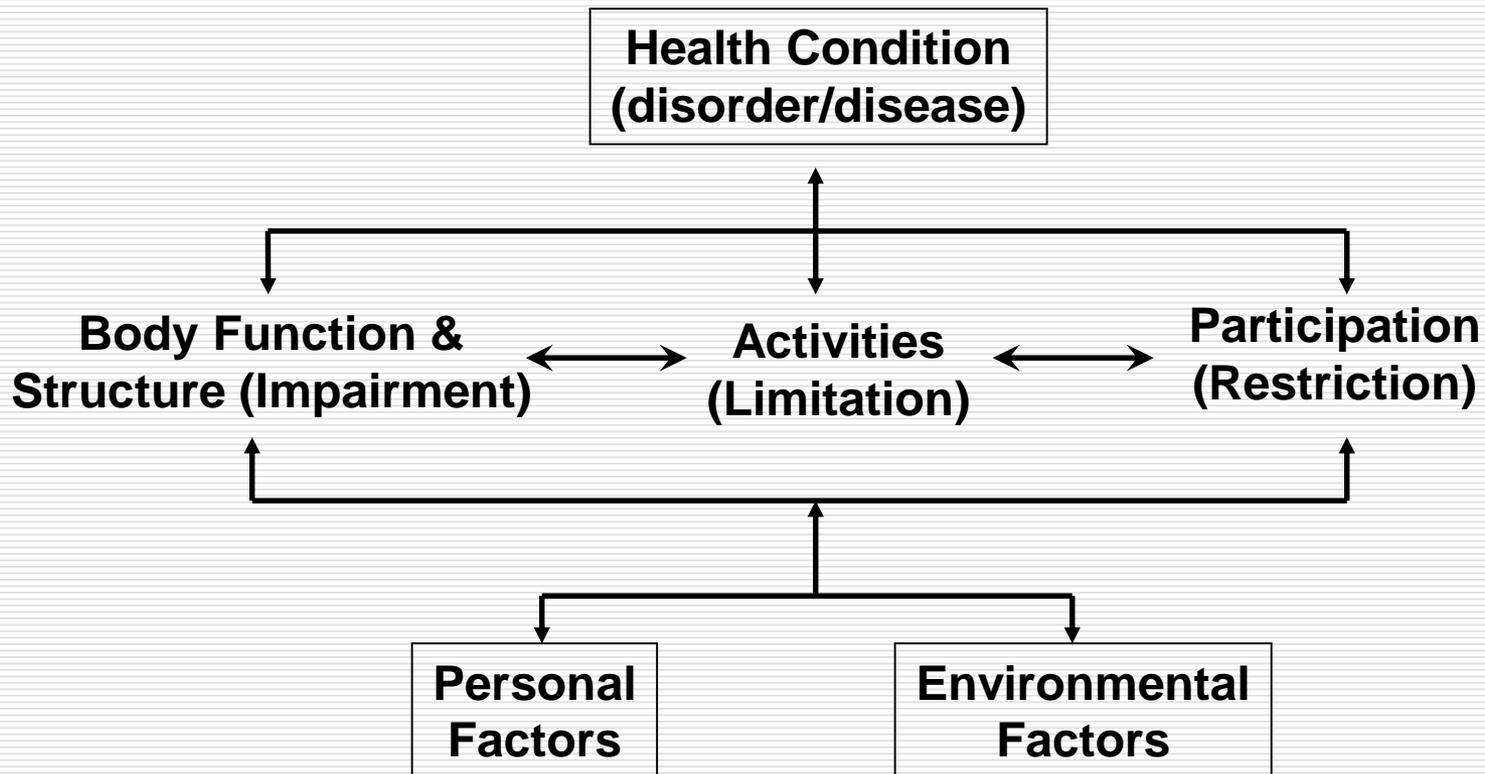
# The Washington Group (WG)

- June 2001: UN International Seminar on the Measurement of Disability

- WG established as a City Group under the aegis of the UN Statistical Commission to:
  - address the need for population based measures of disability
  - foster international cooperation in the area of health and disability statistics
  - produce internationally tested measures to monitor status of persons with disability
  - incorporate disability into national statistical systems

# The WG questions

WG questions are developed

- to collect internationally comparable data based on the ICF model

- that fulfill the monitoring requirements established by the UN Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals.

# The ICF Model - 2001



- **WG Short Set**
- **WG Extended Set**
- **UNICEF/WG Child Functioning Module**

**Health Condition (disorder/disease)**

**Body Function & Structure (Impairment)** ↔ **Activities (Limitation)** ↔ **Participation (Restriction)**

**Personal Factors**

**Environmental Factors**

- **UNICEF/WG Module on Inclusive Education**
- **ILO/WG Disability Module for LFS**

Source: World Health Organization, 2001
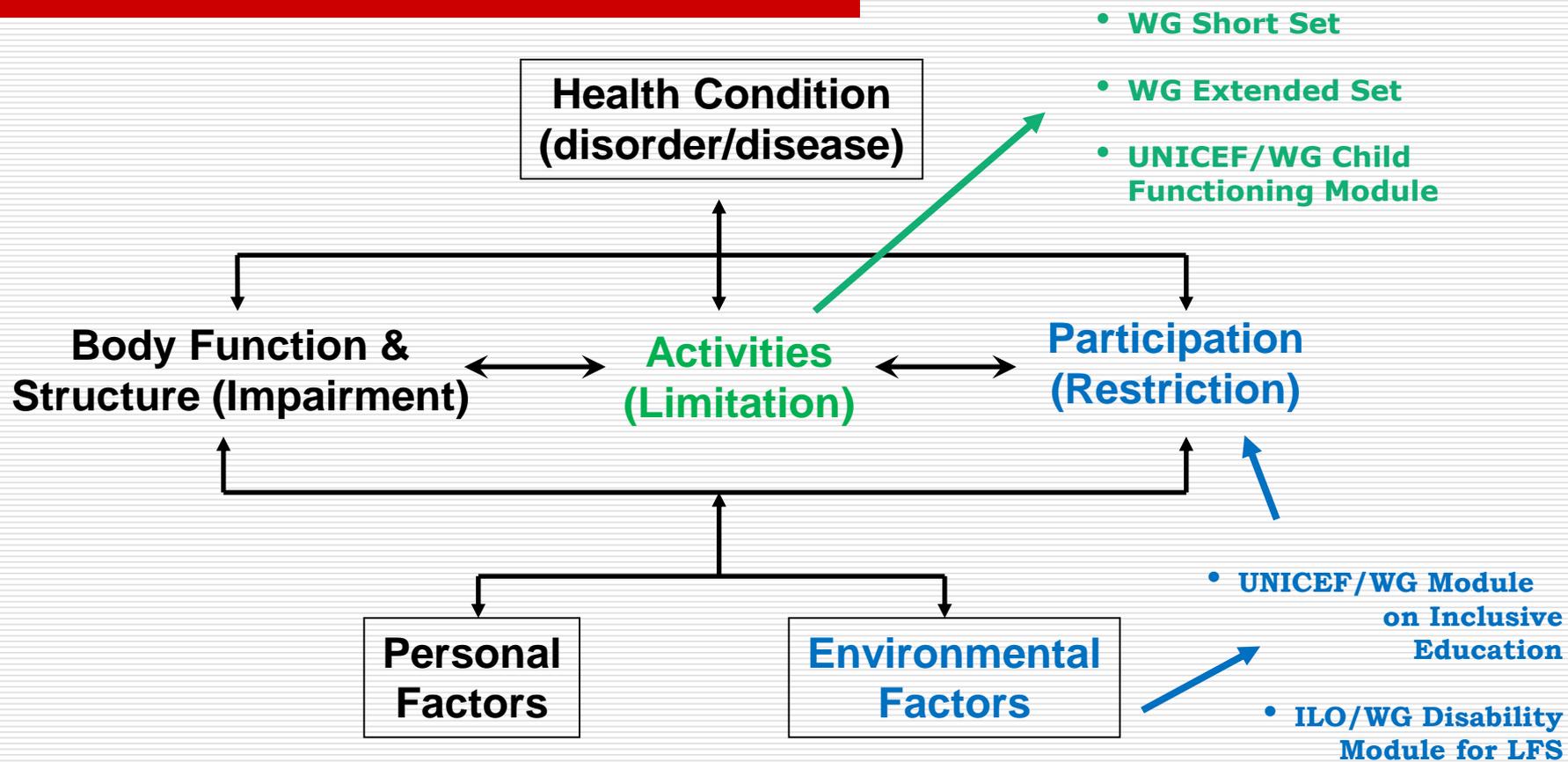
# WG Data Collection Tools:

- **Short set** on functioning: adopted in 2006

- **Extended set** on functioning for adults: adopted 2010

- WG/UNICEF Module on **Child Functioning**: adopted 2016

- WG/UNICEF Module on **Inclusive Education**: in testing

- WG/ILO Disability module for **inclusion on labor force surveys**: in testing

- Module on Psychosocial functioning (Mental Health): under development

# WG Short Set questions

Because of a health problem:

1. Do you have difficulty seeing even if wearing glasses
2. Do you have difficulty hearing even if using a hearing aid?
3. Do you have difficulty walking or climbing stairs?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty with (self-care such as) washing all over or dressing?
6. Using your usual language, do you have difficulty communicating (for example understanding or being understood by others)?

**Response categories:**   No - no difficulty
Yes - some difficulty
Yes - a lot of difficulty
Cannot do at all

# WG Extended Set

- new domains of functioning : upper body functioning, affect, pain, and fatigue

- additional information on the domains already covered by the short set: seeing, hearing, walking, remembering or concentrating, self care, communication,

- information on the use and impact of assistive devices, thereby beginning to establish a link between functioning and the environment.

About *35 questions* on *11 different core domains* that were selected based on their universality and commonality across cultures and countries at various stages of economic development.

# WG/UNICEF Child Functioning Module

- Purpose
  - To to identify the sub-population of children (aged 2-17 years) with functional difficulties. These difficulties may place children at risk of experiencing limited participation in a non-accommodating environment.
- Aim
  - To provide cross-nationally comparable data
  - To be used as part of national population surveys or in addition to specific surveys (e.g., health, education, etc.)

# Selected domains

1. Seeing*
2. Hearing*
3. Mobility**
4. Self-care (5-17)*
5. Dexterity (2-4)
6. Communication*
7. Learning (and Remembering 5-17)*
8. Emotions (5-17)**
9. Behaviour
10. Attention (5-17)
11. Coping with change (5-17)
12. Relationships (5-17)
13. Playing (2-4)

\*   Comparable WG SS questions   34
\*\* Comparable WG ES questions

# Monitoring the UN CRPD through data disaggregation

WG questions fulfil two specific data needs:

- to describe disability data as a <u>continuum</u> of functioning based on graded responses to questions in the functional domains, and

- to define a <u>cut-off</u> (or a set of cut-offs) that can be agreed upon internationally in order to disaggregate outcome indicators (e.g. access to education, employment) by disability status

This allows for the calculation of prevalence rates and disaggregation.

# Focus on Equalization of Opportunities

- Seeks to identify all those *at greater risk than the general population for limitations in participation*.

- Disability used as a <u>disaggregation variable.</u>

% Employed
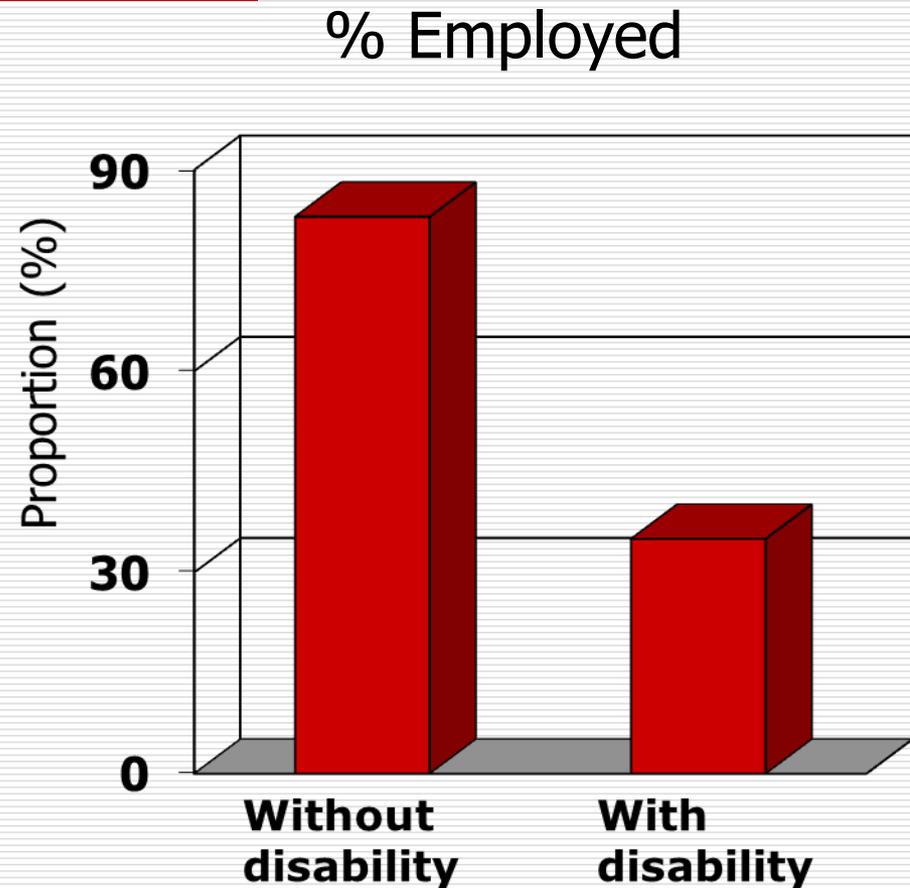
# Mainstreaming disability statistics

- WG questions can be added to any on-going data collections;

    - Can be used in any national or subnational survey (health, labor force, income & expenditure, DHS, MICS etc.)

- Once the WG questions become integrated into core statistical systems – disaggregating outcomes (education, employment etc.) by disability status becomes routine

For more information about the WG:
**http://www.washingtongroup-disability.com/**

# UNCRPD and INDICATORS

# Italy - National Context

- Italy signed both CRPD and OP CRPD on 30 March 2007 and ratified both on 15 May 2009.

- The focal point for matters relating to the implementation of CRPD in Italy is the **Directorate-General for Inclusion, Social Rights and Social Responsibility of the Ministry of Labour and Social Policies.** It coordinates with the other ministries and with regional and local authorities.

- Italy has established one independent mechanism to promote, protect and monitor the implementation of the Convention: the **National Observatory on the Situation of Persons with Disabilities**. It is operational since 2010.

# Italy - National Observatory: AIMS

- to promote the implementation of the UNCRPD

- to prepare a *two-year action plan* for the promotion of the rights and the integration of PwD to give effect to national and international legislation

- to promote the collection of statistical data to describe the situation of PwD

- to prepare a reports on the implementation of disability policies (art. 41, L.104/92)

- to promote studies/researches that can contribute to identifying priority areas to which direct actions and interventions for promoting the rights of PwD.

# Italy - National Context

In the 1992 the **Framework Law n.104** established a lot of services and intervention in different social contexts to reach a complete inclusion of PwD.

Education and school integration

Architectural barrier

Work and employment

Areas of action

Accessible information

Prevention and Precocious diagnosis

Prosthesis and technical aids

Health and rehabilitation care
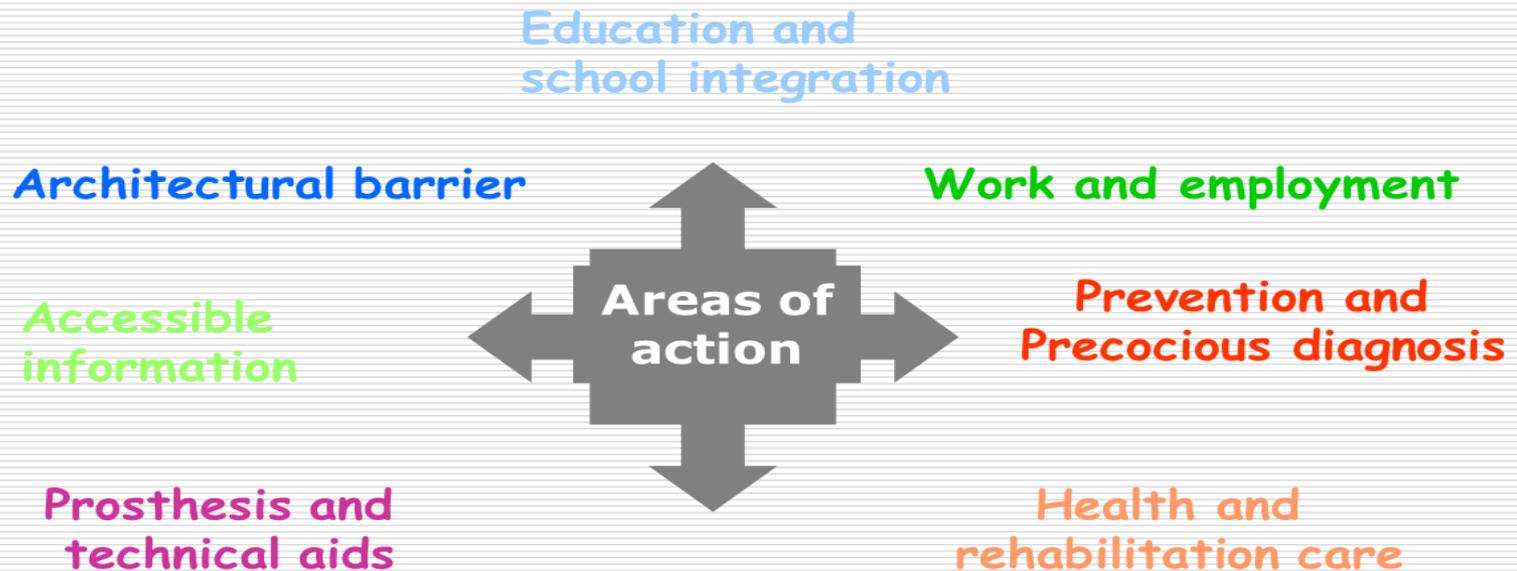
Serious disability          Social inclusion

# Guideline principles for selecting indicators

o Initially, to focus only on the objectives related to **living conditions or activities and participation** that are currently documented through **population surveys** or inferred on the basis information from **administrative records.**

o The selection criteria of sources and indicators ensure the appropriateness to the objectives in terms of: **reliability** (statistical quality), **relevance** (coherence with the objectives), **effectiveness** (consistency with the objectives), **periodicity** (responsiveness to the frequency of analysis).

o **Relative comparisons** i.e. assessments based on the comparison between the levels of activities and social participation observed in the population with and without disabilities.

# To monitor the UNCRPD

o    In collaboration with the National Observatory, Istat is developing a **proposal of indicators** based on the work already done within the framework of SID.

✓ To cover all areas of monitoring under the Convention
✓ To highlight information gaps

- ACCESSIBILITY
- PARTICIPATION
- EQUALIZATION OF OPPORTUNITY
- WORK AND EMPLOYMENT
- EDUCATION
- SOCIAL PROTECTION
- HEALTH

# Number of indicators by UN areas of interest

| Areas | UN – Convention articles | | | | | | |
|---|---|---|---|---|---|---|---|
| | Accessibility At.9 | Participation Art. 29 Art. 30 | Equalization of opportunity Art. 5 | Work and employment Art.27 | Education Art. 24 | Social protection Art. 28 | Health Art. 25 |
| Education | 3 | | | | 5 | | |
| Work | | | 3 | 6 | | | |
| Everyday Life | 18 | | 22 | | | | |
| Economic wellness | | | 2 | | | 5 | |
| Social Life | 6 | 16 | 10 | | | | |
| Health | | | | | | | 6 |
| Services | 7 | | 12 | | | 4 | |

## Education

| Indicators | Sources | Article | Title of article |
|---|---|---|---|
| Persons of 15 years old by presence of disability, education level and gender | CDS | art. 24 comma 1 | **Education** |
| Persons of 15 years old by presence of disability, education level and age group | CDS | art. 24 comma 1 | **Education** |
| Persons of 15 years old by presence of disability, education level and regions | CDS | art. 24 comma 1 | **Education** |
| Students by presence of disability, school level and regions | MIUR | art. 24, commi 2 e 5; | **Education** |
| Students of the upper secondary school by presence of disability and type of secondary school | MIUR | art. 24, commi 2 e 5; | **Education** |
| Persons aged from 15 to 64 years old not enrolled in training courses by presence of disability, type of barriers to continue the study | CDS | art. 9 comma 1; art. 20; art. 24 commi 2 e 5 | **Accessibility** |
| Persons aged from 15 to 64 years old by presence of disability and type of aids - received or needed - to study for a professional qualification or a degree | CDS | art. 9 comma 1; art. 20; art. 24 commi 2 e 5 | **Accessibility** |
| Schools by architectural features | Ad hoc survey | art. 9 | **Accessibility** |

The United Nations Convention on the Rights of Persons with Disabilities was ratified by the Italian government with Law 18 of March 3, 2009.

Article 31 "Statistics and data collection" of the Convention obliges the States Parties &ldquo to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention". Furthermore, "the information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights".

In compliance with this Article, here are – in an accessible format – the main indicators for monitoring the implementation of the Convention. These indicators have been agreed within the National Observatory on the Condition of Persons with Disabilities-Ministry of Labour and Social Policy based on available official data sources.

http://dati.disabilitaincifre.it/

## Education

Persons aged 15 years and over by presence of disability, level of education, gender and age class
2013

Persons aged 15 years and over by presence of disability, level of education and region
2013

Average number of children with disabilities per special education teacher, region and school level
2015

Average number of weekly hours of teaching for pupils with special education teacher by place in which they are carried out, presence of autonomy, geographic distribution and school level
2015

Pupils with disabilities by participation in overnight school trips, geographic distribution and school level
2015

## Work and Employment

Persons with disabilities aged 15 years and over by self-declared employment status, gender and age class
2013

Persons with disabilities aged 15 years and over by self-declared employment status and region
2013

Working persons aged 15 years and over by presence of disability, occupational position and age class
2013

# Strategies to fulfill art.31 UNCRPD
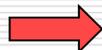
**Short term** → Use of all available official data sources to cover as much areas of interest as possible.
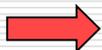
**Middle term** →
- ✓ To exploit available data sources
- ✓ To develop a work plan to cover information gap
- ✓ To implementation of new data sources to cover the request of new information
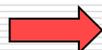
**Long term** →
- Improvement in access to and use of administrative sources
- Working at international level to implement comparable definition, measure and analysis of disability

# Final remarks

- We need disability data  (and time series) that are **accurate**, **consistent**, **reliable**, **updated**, **accessible** and **internationally comparable**.

- Data collection should cover **all aspects** of the ICF disability model.

- Questions able to identify PwD (in line with ICF) should to be added to **any on-going data collection**, becoming a core variable for all surveys

- Disaggregating data on education, employment, etc. by disability status can become routine only on the basis of questions that **are fully integrated into core statistical systems.**

- We need **disaggregated disability data to verify that PwD** actually participate  into society "on an equal basis as others".

# Solutions to barriers in accessibility

Elizabeth O'Ferrall

# Solutions to barriers in accessibility

- Welcome
- Introduction
- CRPD and Article 9 – Accessibility
- Standards ( CEN/CENELEC) in support of Article 9
- Background to Standardisation
- Case Study on Web accessibility
- Irish National Standard and Case Studies showing implementation
- Interactive exercise for participants on visual clarity of text

-

# Solutions to barriers in accessibility

### ► **INTRODUCTION**

► Meet the "Normals Family" – a brief introduction to humans , their diversity and the environment that they live ,participate and interact with.

https://youtu.be/A88E4DH2asQ

# Solutions to barriers in accessibility

## Focus:

## UN Convention on the Rights of Persons with Disability

- Article 9 – Accessibility

# Solutions to barriers in accessibility

## Article 9……Extract -

- 1. To enable persons with disabilities to live independently and participate fully in all aspects of life…………

These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

- …. (b) Information, communications and other services, including electronic services and emergency services.

- ….. (h) Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

# Solutions to barriers in accessibility

## EUROPEAN STANDARDS IN SUPPORT OF ARTICLE 9 of the CRPD

# Solutions to barriers in accessibility

## LEGISLATION AND STANDARDS

- Directive (EU) 2016/2102 Accessibility of the websites and mobile applications of public sector bodies

- At European level the EU Commission issue Standardisation Mandates/Requests to CEN ,CENELEC & ETSI who are technical Standards Organisations to develop standards

# Solutions to barriers in accessibility

Standardisation Mandates/Requests in support of CRPD and of people with disabilities

- Mandate M376 ….. In support of accessibility requirements for public procurement of products and services in the ICT domain

- Mandate M420….. In support of European accessibility requirements for public procurement in the built environment

- Mandate M473 --- to include "Design for All" in relevant standardisation initiatives

- Mandate M554….on the accessibility of the websites and mobile applications of public service bodies

# Solutions to barriers in accessibility

**THE LINK BETWEEN LEGISLATION AND STANDARDS (standards supporting legal instruments )**

European ( and National ) Standards developed or under development

- EN 301549 …. Accessibility requirements suitable for public procurement of ICT products and services
- prEN 17161…… Accessibility following a Design for All approach in products, goods and services – Extending the range of users
- prEN 17210 ….. Accessibility and usability in the built environment-functional requirements

# Solutions to barriers in accessibility

## CASE STUDIES

# Solutions to barriers in accessibility

**FOCUS OF THESE CASE STUDIES ARE IN RELATION TO THE  CRPD : ARTICLE 9 (1) (B) AND (H)**

- …..elimination of obstacles and barriers to accessibility,

- In relation to :

- …. (b) Information, communications and other services, including electronic services and emergency services.

- ….. (h)  …..distribution of accessible information and communications technologies and systems ……

# Solutions to barriers in accessibility

## CASE STUDY EXAMPLE – WEBSITE ACCESSIBILITY

Legal & General, a UK supplier of financial services, were aware that their website was not designed to be as accessible and usable as it could be so that the widest range of users could access , understand and use it.

- In 2005 they undertook to improve the entire user-experience of their website

- Applied a "user centred approach during the evaluation

- They evaluated how customers used the site, using web analytics and relevant software.

- They carried out more general research on the needs of their customers

# Solutions to barriers in accessibility

## CASE STUDY – WEBSITE ACCESSIBILITY CONTINUED

- Legal & General, - Who were and who could be their customers
- The Demographics of the population in the UK in 2005:
  - 3.2 million people in Britain have difficulty using inaccessible websites;
  -  6 million have dyslexia;
  - 1 person in 3 is over the age of 50;
  - 3 million people speak English as a second language;
  -  1.5 million lack basic language skills;
  - 5.2 million adults have sub-GCSE level English

# Solutions to barriers in accessibility

## CASE STUDY – WEBSITE ACCESSIBILITY CONTINUED

Benefits and Outcomes of the changes to the  website

- an increase of 13,000 visitors to their site each month.
- Online sales of insurance products increased by 90%.
- Saving of  £200,000 each year on website maintenance.
- The entire project delivered 100% return-on-investment within just 12 months.

# Solutions to barriers in accessibility

## IRISH NATIONAL STANDARD , TOOLKITS & CASE STUDIES SHOWING IMPLEMENTATION

# Solutions to barriers in accessibility

## BACKGROUND

- Irish Standard (I.S.) 373:2013 'Universal Design for customer engagement in tourism services' was developed by NSAI

- It was supported with Toolkits which were developed in 2013 by the National Disability Authority

- A number of Case Studies were developed in partnership with Fáilte Ireland to show the value to  service providers to using the toolkits

NOTE : Along with the  CRPD , the Irish Disability Act of 2005 was a driver for developing this Irish Standard

# Solutions to barriers in accessibility

## ➥ BACKGROUND

➥ SCOPE of the Standard (I.S.) 373:2013

➥ provides requirements and guidance in the application of **Universal Design of products** and **services** for **customer communications** for use by Tourism **Service** Providers. It is intended to assist them to make their products and services for **communications more accessible and usable** by **as many people as possible** without the need for additional adaptation or specialised design.

# Solutions to barriers in accessibility

By considering the diverse needs and abilities of all throughout the design process, Universal Design creates products, services that meet peoples' needs

# Solutions to barriers in accessibility

- Impairments that either reduce or stop the ability of persons with a disability participating in society



**Vision**
Ability to see or process information

**Hearing**
Ability to hear or process acoustic information

**Motor**
Ability to interact with a device accurately and quickly

**Cognitive**
Ability in mentally demanding areas (reading, memory, attention, language)

# Solutions to barriers in accessibility

- Some impairments are short-term



**Vision**
Forgot my glasses

**Hearing**
Watching a video in a noisy environment

**Motor**
Temporary injury such as a broken wrist

**Cognitive**
Hangover!

# Solutions to barriers in accessibility

- Some impairments are long term impairments or disabilities



**Vision**
Blindness, Low Vision & Colour Blindness

**Hearing**
Hearing Loss

**Motor**
Dyspraxia, RSI, Arthritis, Cerebral Palsy

**Cognitive**
Down's Syndrome, Asperger's and Dyslexia

# Solutions to barriers in accessibility

## I.S. 373 Standard content

- Written communication
- Face-to-face , telephone and video communication
- Electronic and web-based communication

# Solutions to barriers in accessibility

## I.S. 373 Standard -Written communication

- provides guidance on communicating with customers using written communication;

- provides guidance on a range of topics from formatting and writing guidelines, to form and signage design.

# Solutions to barriers in accessibility

**I.S. 373 Standard - Face-to-face , telephone and video communication**

➡ provides guidance on communicating with customers verbally and awareness around non-verbal behaviour (specifically body language).

# Solutions to barriers in accessibility

## I.S. 373 Standard - Electronic and web-based communication

- provides guidance to authors and editors who write web content, designers and developers of web content

- guidance on topics including social media, SMS messaging and emailing.

# Solutions to barriers in accessibility

**I.S. 373 Standard summary**

**Sets out requirements and recommendations for:**

- **Written communication** – use plain English, text size, use of colour or bold to highlight key information

- **Face-to-face – verbal communication** in relation to behaviour and attitude, use of alternative means of communication , use of visuals

- **Electronic and web based communication** – information clear and concise, easy to navigate ,accessibility focused apps should be fast to load, use of plain English in responding to emails

# Solutions to barriers in accessibility

- Making documents and web pages accessible-

- Examples

**Forms:** Labels, Keyboard access, Clear instructions and effective error handling are essential!

**Keyboard Access & Visual Focus:** Many people cannot use a mouse and rely on the keyboard to interact on the web.

**Headings:** Web pages often have sections of information separated by visual headings (e.g. "Headings" being bigger and bolder)

**Image Text Alternatives:** Text alternatives ("alt text") convey the purpose of an image, including pictures, illustrations, charts, etc.

**Page Titles:** The first thing screen readers say when the user goes to a different web page is the page title.

**Menus:** The primary form of navigation on a web page. Should be easy to understand for all accessibility tools.

# Solutions to barriers in accessibility

- **Toolkits on Communications**

# Solutions to barriers in accessibility

- Reference Material


- Customer Communications Toolkit for the Public Service – A Universal Design Approach (Published by the National Disability Authority (NDA), Ireland )

- http://universaldesign.ie/Products-Services/Customer-Communications-Toolkit-for-the-Public-Service-A-Universal-Design-Approach/

# Solutions to barriers in accessibility

**TOOLKITS** to support the implementation of good communication following a Design for All approach

- Provide guidance to businesses/organisation in how to apply a Universal Design approach for communications with their customers

- -Includes guidance on general writing style principles, verbal and non-verbal communications, design of forms and documents, web and social media content and how to display signage.

- Gives advice on the provision of the highest quality of online services

# Solutions to barriers in accessibility

- Toolkits to support the implementation of good communication following a Design for All approach

- Short Video – use of customer communications toolkits

- https://www.youtube.com/watch?v=dn7yiTgsJFs

# Solutions to barriers in accessibility

**Exercise - Communication**

➡ Means of communications in your workplace with your customers

# Solutions to barriers in accessibility

## ■ **Exercise**

- ■ Working in pairs, address the following questions :

- ■ Is there evidence in your work environment where communications systems such as face-face , written , telephone and web based is accessible and usable by a wide range of users

  (a) Written communications – Forms that are used by customers

- ■ (b) Telephone communication – interaction with persons that have a hearing impairment

- ■ (c) Your workplace website – is it accessible by a wide range of users?

# Solutions to barriers in accessibility

## ■ **Exercise cont'd**

(a) Written communications – Forms that are used by customers

■ (b) Telephone communication – interaction with persons that have a hearing impairment

■ (c) Your workplace website – is it accessible by a wide range of users?

■ (d) face-to-face communications – is there alternative forms of communication provided

# Solutions to barriers in accessibility

**➡ Exercise- Review & Feedback**

➡ (a) Written communications

➡ (b) Telephone communication

➡ (c) Your workplace website

➡ (d) face to face communication

# Solutions to barriers in accessibility

## Summary – Information & Communication

- Provide printed information in alternative formats- Braille, Audio, Video, electronic formats, sign language

- Use clear and concise language in all communications

- All information should be free of stereotypes and discriminatory notions

- Printed publications/forms etc should have clear typeface and large font size, adequate contrast between background and text

- Provide communication support , translators, deafblind interpreters, note-takers, speech-to-text reporters

- **\*\* TRAINING STAFF WHO INTERACT WITH A WIDE RANGE OF CUSTOMERS INCLUDING PERSONS WITH DISABILITIES\*\***

# Solutions to barriers in accessibility

- **Toolkits for Communications**

- Available to download free at this website
- http://universaldesign.ie/Products-Services/Customer-Engagement-in-Tourism-Services/

# Solutions to barriers in accessibility

## Document Accessibility Toolbar (DAT)

- DAT can be USED to make documents accessible.

- https://www.youtube.com/watch?v=sbDVwbq0YT0

# Solutions to barriers in accessibility

**Interactive Exercise**

ACTIVITY

- The Cambridge exclusion calculators and SEE-IT tool
- http://seeit.inclusivedesigntoolkit.com/

# Solutions to barriers in accessibility

## JUST SOME STATISTICES TO FOCUS THE MIND

- Ireland, the 2011 census showed that 600,000 people reported having a disability, which equates to 13% of the population

- Europe, 80 million people have declared a disability

- 224,000 people in Ireland alone (and 285 million globally) have a degenerative eye condition that can't be corrected.

- Colour blindness affects 1 in 12 men and 1 in 200 women globally.

- There's over 2.7 million people in the UK alone with colour blindness, equating to 4.5% of the entire population.

# Solutions to barriers in accessibility

## ➡ INTERACTIVE EXERCISE

ACTIVITY - Sight Exclusion Estimator

**SEE-IT stands for Sight Exclusion Estimator**

SEE-IT stands for Sight Exclusion Estimator - Interactive Tool. This tool can be used to assess the visual clarity of text or graphics in documents. It estimates the number of people who would be unable to see such designs/documents comfortably.

- ➡ The Cambridge exclusion calculators and SEE-IT tool
- ➡ http://seeit.inclusivedesigntoolkit.com/

# Solutions to barriers in accessibility

- Instructions - Work in pairs

- - You need a SMART phone or lap top and log onto
- http://seeit.inclusivedesigntoolkit.com/

- A measuring tape
- Paper

# Solutions to barriers in accessibility

- Start

## How?

Start by preparing for your assessment:

[ Prepare ]

# Solutions to barriers in accessibility

- Start

**Next steps**

Now calibrate your vision:                          [ Calibrate ]

# Solutions to barriers in accessibility

- Start

**Next steps**

Now calibrate your vision:    | Calibrate |

# Solutions to barriers in accessibility

- Start

## Calibrate to your vision

Different people have different levels of vision ability. To make a calibrated assessment, it is first necessary to determine the vision ability of the assessor, by reading some test-chart letters. To do this now, please follow the instructions below.

1. On your phone, set your screen brightness to maximum.

2. Unroll your tape measure to the 10 cm mark, and use the button to lock it off. Place it next to the image shown below.

3. Use the — and + buttons below to alter the size of the image of a tape measure, until the 3 and the 7 cm marks line up with the real tape measure. This makes sure that test-chart letters can be displayed on your screen at exactly the right size.

| — | + |
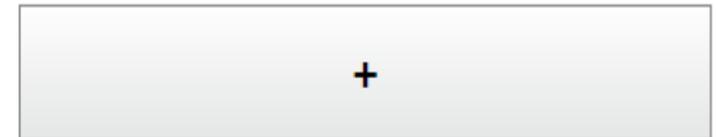
# Solutions to barriers in accessibility

4. Roll the tape measure out along the floor, so that the metal end is touching a wall. Press the button to lock the tape measure off.

5. Prop this phone against the wall at eye-level. This is most easily achieved by asking an assistant to hold the phone against the wall at the right height.

If you wear glasses for distance (e.g. driving), then wear them for this test. Walk backwards and forwards until you find the furthest distance away from the phone where the letters below are **comfortable** to read.

# E N F H R

1. Note the position of your big toe on the tape measure (in cm).

2. Enter this number in the box below. It will be stored on this device for future reuse, and is specific to your eyesight.

Enter your Calibration Distance (cm) in the box below:

85

Set

**Your calibration distance is stored as 85 cm.**

If you want to design something that is comfortable for at least 90% of the population, ensure that it is comfortable for you at a distance of at least 47 cm.

# Solutions to barriers in accessibility

**Next steps**

Now, assess your design:

Assess

# Solutions to barriers in accessibility

- **FEEDBACK**

# Solutions to barriers in accessibility

A good design
will communicate
both
visually and verbally
effectively
while bad design leaves one or the other out.

# Solutions to barriers in accessibility

**EXAMPLES OF BAD DESIGNS V GOOD DESIGNS**
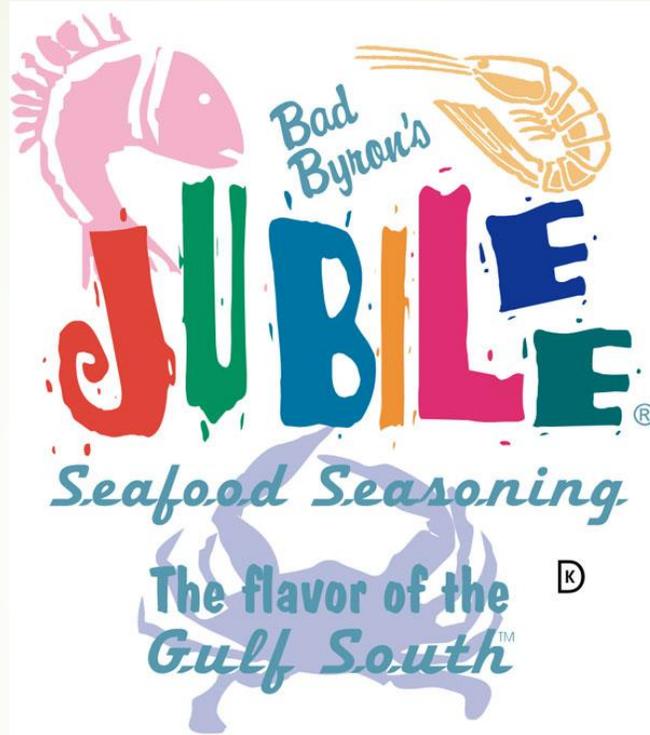


ORIGINAL DESIGN      UPDATED DESIGN

www.GetCreativePC.com

# Solutions to barriers in accessibility

**EXAMPLES OF BAD DESIGNS V GOOD DESIGNS**

# Solutions to barriers in accessibility

**EXAMPLES OF BAD DESIGNS V GOOD DESIGNS**

# Solutions to barriers in accessibility

"Good design is about effective communication, not decoration at the expense of legibility."

- Vitaly Friedman

**inspireUX**

# Solutions to barriers in accessibility

- Thank you for your attention

- Questions

- Elizabeth.oferrall@nsai.ie