

# Challenges to implement the Right to Legal Capacity of persons with disabilities

EU Disability Law and the CRPD, Trier, European Academy of Law,  
14 December 2012  
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## Inclusion Europe

- The European Association of Persons with Intellectual disabilities and their Families
- Founded 1989
- Regional Member of Inclusion International
- Members in all 27 EU countries
- 8 Members in accession and non-EU countries
- 13 Member organisations of self-advocates
- [www.inclusion-europe.org](http://www.inclusion-europe.org)



## About making decisions

- Most decisions we make are not rational.
- External influences: culture, preferences, social relations
- Need for advice – we often seek expertise
- Decisions may not be in our “**best interests**”
- Right to make mistake, to take bad decisions



## The place of article 12 in the CRPD

- Highly debated article during the negotiations
- Revolutionary article: it challenges the concept of rational personhood
- Supports equal opportunities, independence, autonomy and inclusion into society
- Essential article for the realisation of other rights enshrined in the CRPD: e.g.: Article 19, Article 29.



## Article 12 - meaning

- Article 12(1) of the CRPD states that:  
States Parties **reaffirm** that persons with disabilities have the right to recognition everywhere as persons before the law.  
= 'legal personality,' which Volio defines as an "individual's '**personhood**' in society."  
See Article 16 of the *International Convention on Civil and Political Rights* (ICCPR)



## Article 12 - meaning

- Article 12(2) states that:  
States Parties shall recognize that persons with disabilities enjoy **legal capacity** on an equal basis with others **in all aspects of life**.  
= **capacity to have rights AND capacity TO ACT**, that is to say make legally binding arrangements with others: personal care, health care, property, finances, financial credit (see also Art. 12 (5)).



## Making decisions about



Health Care



Finances/Property



Personal Life – where and how to live, work, be supported; relationships, family



## Article 12 - meaning

- Article 12(3) states that:  
States Parties shall take **appropriate measures** to provide access by persons with disabilities **to the support** they may require in exercising their legal capacity.  
= support to take decisions



## Article 12 - meaning

- Article 12 (4) States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for **appropriate and effective safeguards** to prevent abuse:
  - respect the rights, will and preferences of the person
  - free of conflict of interest and undue influence
  - proportional and tailored to the person's circumstances
  - subject to regular review by an authority
  - apply for the shortest time possible



## Article 12 : a new paradigm

- Article 12 UNCRPD requires a real shift towards a Human rights approach of legal capacity, that means: **replacing substitute decision-making by appropriated supports and safeguards.**
- Legal recognition of universal legal capacity: right to full legal capacity by all persons without discrimination on the basis of disability
  - No more plenary guardianship
  - No automatic loss of rights
  - Supported decision-making



## Article 12 – consequences

- **Article 12 calls for an end to substitute decision-making laws where they provide for this determination on the basis of disability.**
- **Article 12 obliged States to provide people with disabilities the supports they need to exercise their legal capacity** (with supported decision making people have full legal capacity)



## Challenges to implement Art. 12

- **Economic and Financial reasons**
- **Attitudes in the society towards people with intellectual disabilities**, including the lack of knowledge on the meaning of legal capacity e.g. Distinction between support person and guardian; what are the necessary safeguards in a supported decision-making model...
- **Legal framework**
- **Political will**



## The situation with regards to legal capacity in Europe

- Variety of situations – from very progressive models to old-fashion ones.
- A general trend of reforms to implement „modern guardianship“ laws
- Attempts to include in legislation models of supported-decision making – impulse from Central and Eastern European Countries, more recently also Ireland



## Models based on self-determination

- Example from Germany: Betreuungsgesetz (1992)
- No more legal incapacitation procedure
- Legal assistance and representation – facilitate self-determination
- No restriction of the individual's ability to act
- But : the Betreuer (supporter) can act as a proxy in legal matters if he/she thinks it is necessary.



## Modernized guardianship laws

- France: Guardianship Law of 2007 (Civil Code) includes several amendments, such as:
  - The person must be listen during the incapacitation procedure
  - Revision every 5 years
  - For decisions about health and place to live, the guardian is only providing information and support but is NOT taking decision
  - Training, controls, evaluation and remuneration of guardians are better regulated



## Modernized guardianship laws

In 2004, Italy introduced a flexible measure of legal support alongside the traditional guardianship

*Amministratore di sostegno (support manager)*

- Does not incapacitated the person
- Support for better (future) quality of life
- Appointed by the judge (family members when possible) – free procedure
- Scope of the assistance is tailored to the individual's needs.





## Traditional old-fashion laws

- Mainly Central and Eastern European Countries – still Laws from the 60s
- Complete deprivation of rights „legal death“– no right to vote, to marry, and (in some cases) right to work
- Issue linked with long-term residential care
- Conflicts of interests
- No reviews
- No access to legal remedies (appeals)



## Moving forwards

- Most countries are/will review their laws on legal capacity in the coming years – driven force is the UN CRPD and Human rights issue
- Important supreme Court decisions in Poland and in the Czech Republic
- Huge debates about the introduction of supported-decision making provisions
- Pilot projects are currently running
- We need to build practice models to exchange and share



## Example: new Civil Code in the Czech Republic

- The new Civil Code (will enter into force in January 2014) includes:
  - Advance directive
  - Support in decision-making
  - Representation by a family member
  - Appointed guardian without restriction of legal capacity (legal representation)
  - Partial guardianship (decision to be reviewed every 3 years)



## Advocacy work on legal capacity

- Define and agree on a set of recommendations to illustrate the core principles underpinning Article 12.
  - What are the **core elements** of SDM?
- Offer a platform of discussion for people with disabilities to support them to shape and influence reforms of guardianship laws.
- Work towards other groups concerned by reforms of guardianship laws (elderly people...)



## Principle 1 : Everyone is capable of taking decision

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



## Principle 2: Recognition of all forms of communication

- Recognition in legislation of all forms of communication is a pre-requisite for a model of supported decision-making.
- The way how people communicate should not be a reason to question their decision-making ability.
- All individuals have will and intentions.
- This provision should be clearly included in the legislation.



## Good practices to consider

- Examples of good practices with people with severe and/or combined disabilities, having no verbal communication
  - Keep **records of the person communication methods and forms, will and habits**
  - **Personal identity – story**: resource to determine his or her need of support NO medical or psychological statement
  - Using **witness** to report about trust relationships



## Principle 3: Neutral test of capacity to enter an agreement

- Functional, decision-specific test must be applied in assessing or finding incapacity.
- Other party's interests and liability concerns do not justify removing a person's decision-making rights
- Capability test (with support and duty to accommodate) must be done for the specific decision (safeguard)



## GOOD PRACTICE FROM BC

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



## Principle 4: Every effort should be made to support people to exercise legal capacity

- The legal concept of **reasonable accommodation** (Article 5 CRPD)
- States Parties have an obligation to establish systems of support and to impose **duties to accommodate**, in order to assist persons with intellectual disabilities in the exercise of their legal capacity.



## Principle 5: Individualised and Person centred Approach

- A wide range of support services must be available and sustainable to provide support
- Individual and Flexible measures: for each person, there is a specific answer
- Supported decision-making should be arranged in a flexible way:
  - One or a group of tasks: daily financial affairs, personal affairs, health, housing, legal representation
  - One or more persons could be appointed as supporters with different tasks.



## Good practice from Germany

- Procedural steps (Familienverfahrgesetz) :
  - The Guardianship Court must investigate, as soon as it gets notice by anybody about a person in need, § 26 FamFG
  - The person concerned is informed about the procedure, § 278 sec. 2 FamFG
  - Courts can order a Report from the Local Authority for Betreuung, about the Life Situation of the person concerned and the necessity of Betreuung, § 8 BtBG (BetreuungsbehördenG)



- Personal Interview of the person concerned by the Judge, usually at the permanent residence of the person, not in the Court, § 278 sec. 1 FamFG
- If necessary, nomination of a Supporter for the Procedure („Curator“), § 276 FamFG
- In addition, there are important provision on access to justice:
  - Anybody who is affected by a procedure of Betreuung has – no matter about his actual capability – legal capacity to act in the procedure, § 275 FamFG
  - Any declarations, applications or complaints of the disabled person have to be considered and dealt with by the „Betreuungsgericht“ as legally valid interventions



## Principle 6: Network as Safeguards

- Support networks can be based on existing trust relationships or on created relationships for people with intellectual disabilities (for example people from institutions).
- Role of third party: to ensure that supporters comply with their legal duties
- Role of the support network in decisions that substantially affect personal integrity and identity (e.g.: health care decisions)?



## Safeguards: Good practice from BC

1. **Representation agreements must be witnessed:** if the agreement is not done with a lawyer, then 2 witnesses are required.
2. A **monitor is appointed** – for routine financial affairs. The **monitor** is a particularly special role. The monitor is there to ensure that the representative is following his or her duties. The monitor may also provide support and help with problem solving if necessary and the law says that no one can prevent the monitor from having contact with the adult.



## Principle 7: Mainstream mechanisms for the protection of the interests of a person

- Using mainstream **mechanisms** for the **protection** of the interests of people with disabilities and making these mechanisms accessible to people with disabilities (consumer protection, patient's rights) is essential.
- Providing information about the existence and availability of such systems in **accessible format**





## Principle 8: Empowerment of people with disabilities

- Family members, carers, professional staff and others should recognize the ability of people with intellectual disabilities to take their own decisions.
- Self-advocates have a role to play for their peers with intellectual disabilities
- Support for **self-advocacy** should be developed already at schools and along the life of people with disabilities.

