

# Access to Justice for persons with Intellectual Disabilities (AJuPID)

## TRAINING MATERIAL<sup>1</sup>

(2016)

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## I. Introduction

About 4,5 million people with intellectual disabilities live in the European Union (EU). That is about as many people as are living in Ireland. Many disabled peoples are restricted in their legal capacity; often they have a legal guardian who takes some or all decisions for them. Their access to justice is also limited due to the lack of accessibility or reasonable accommodation.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) confirms the right to full legal capacity and the right to access to justice in Articles 12 and 13. Persons with intellectual disabilities should be able to decide for themselves and access the justice system on an equal basis with others.

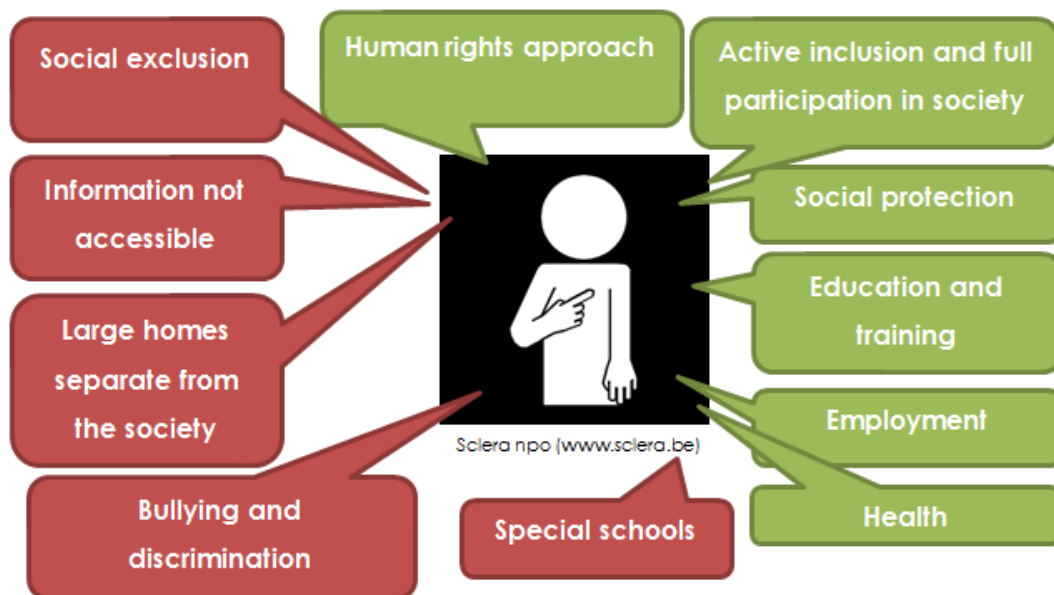
### THE AJUPID PROJECT

The **Access to Justice for Persons with Intellectual Disabilities (AJuPID) project** aims at informing potential supporters as well as staff in the judiciary about the rights of people with intellectual disabilities and how to support them adequately via a Guide of Promising Practices, sensitisation events, a website and training. These tools are based on a research report comparing the legal systems of five countries – Bulgaria, Finland, Hungary, France and Ireland – in access to justice for persons with disability.

The AJuPID project is **co-funded by Directorate-General for Justice of the European Commission**. The project was launched in April 2014 with a duration of two years. It has ten partners from six European countries: Belgium, Bulgaria, Hungary, Ireland, Finland and France.

### THE REAL LIFE OF PERSONS WITH DISABILITIES

Persons with disabilities are often excluded and face barriers hampering their full participation in society and their access to rights. They may find themselves in a situation where others make choices for them and the control over their own lives is limited.



What can we do to support persons with intellectual disability to **maximise choice and control** in their lives? The European Agency for Fundamental Rights says that we should<sup>2</sup>:

- develop legislation and different ways to help people make decisions (**supported decision-making**);
- offer good support for each person;
- offer help for their families;
- support people to have better jobs or to obtain money/services from governments;
- end discrimination so people can work and spend their free time like people without disabilities;
- offer better housing in communities;
- provide better access to information, for example easy read materials;
- support self-advocacy groups and groups that speak up for persons with intellectual disabilities;
- make sure that people can take part in politics and vote;
- offer more information about where and how to complain;
- offer more support when people go to court and talk to a judge.

The overall aim of this training is to raise awareness and sensitise potential supporters, therefore family members, peers and professionals, on how they can better support persons with intellectual disabilities to make their own choices and to defend their rights. The AJuPID training focusses particularly on Art. 12 on legal capacity and Art. 13 on access to justice in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

During the project the following actions were undertaken: design of the training, creation of training materials, translation of the training material, training of trainers, pilot trainings for supporters, evaluation of training.

Major steps and decisions in designing and developing the training and the training materials:

- Determined the competences, skills, knowledge, attitudes
- Determined the training syllabus for the training the trainers and pilot trainings (We assigned a timeframe, as well as content and methodological elements to acquire competencies included in the training. In addition, an outline of the training syllabus was created.)
- Determined guidelines for the development of the training material
- Prepared and approved the training materials
- Elaborated the individual themes of the training based on the outline of the syllabus, i.e. the contents to be taught, the methodologies to be applied and the time to be devoted to them.
- Edited all content, methodological and didactical elements of the training, as well as the presentations, tools, task descriptions, instructions and materials to be used, and the evaluation tools and methods for the training.
- Proofread the training materials by an expert for training in the disability sector.

**Deliverables:** training design and materials, one training for trainers, five pilot training with eight participants (supporters of legal capacity) per country, evaluation.

<sup>2</sup> <http://fra.europa.eu/en/publication/2010/right-political-participation-persons-mental-health-problems-and-persons>  
[https://fra.europa.eu/sites/default/files/fra\\_report\\_on\\_right\\_to\\_vote\\_as\\_easy\\_to\\_read.pdf](https://fra.europa.eu/sites/default/files/fra_report_on_right_to_vote_as_easy_to_read.pdf)



## INSTRUCTIONS FOR THE TRAINERS

The training material is based on a module structure, combines theoretical and practical knowledge and operates with a rich interactive toolbox.

The modules are structured as follows: each module provides an introduction of the **purpose, the key messages** and the **training plan** (*lesson plan*) of the particular topic.

The **training plan** serves as guidance for the trainer in defining the **recommended time frame** and includes the **recommended teaching methods** for each material. The curriculum includes a plethora of teaching methods, varying according to which method supports the subject matter the most. For example, it is recommended to start teaching the theoretical material with a presentation including both the introduction and the key messages (it is recommended to prepare the presentation in a PowerPoint or similar format), for which background material containing the most important information (*handouts*) may be given to the participants.

The curriculum then should be registered by **interactive methods** proposed in the training plan of the particular module, such as brainstorming, video exercises, group work, situational games etc. aimed at registering the participants' knowledge of various materials and different experiences, as well as active engagement with the content. Each exercise of the materials sets out the objective and expected result of the given exercise, which helps the trainer to implement the given exercise. Under "**Tips for the trainers**" the material provides useful information for the trainers about which exercises are helpful in acquiring the material and how to use them. It is important that the interactive practices should be followed by summing up the experiences when possible, which should be recorded on a flipchart. Examples, tools and exercises are available in the **toolbox** which goes with this manual.

The **recommended videos** are always related to the specific topic. It is important that the trainer should encourage participants to focus on aspects of the video related to the subject, and provide a possibility for a structured sharing of experience afterwards. It is very important that if a module suggests viewing a video, we should check whether it is accessible on the URL provided during preparations. If the language (subtitle) of the video is unknown for the participants, but we would like to view it by all means, then we should check whether there is a subtitled or dubbed version of the video or should take care of subtitling during preparations. The trainer must not show any videos that the participants will not understand. In the case of trainings held in each country if there are videos available in the national language of the participants that convey a similar message to that of the one in the curriculum, these videos should be presented. **A youtube playlist is available** with some of the resources.

The training plan recommends the involvement of an **expert of intellectual disability (co-trainer) where possible**. It is recommended to hold a meeting before the training in order to provide an opportunity for the trainer and co-trainer to exchange information, facilitate coordination and to clarify issues related to the implementation and structure of the training. This gives an opportunity to the co-trainer and the trainer to discuss when and how the co-trainer should enter the training. (It is also recommended for the trainer and the co-trainer to exchange their views and discuss the results, as well as their positive and negative experiences.)



**Bibliography** indicates the books and other materials used in the particular module. The trainer may suggest a selected piece of research material and videos listed in the bibliography as recommended materials. As the different modules of the curriculum were created by authors of different nationality, it might be useful for the trainers to add national sources and information (e.g. figures).

There is a **glossary** at the end of the training material. It includes the explanation of the most important concepts that are mentioned in the curriculum.

## REQUIREMENTS FOR THE TRAINING

### a. Knowledge, values and skills

#### Knowledge

The Trainer

- Has an understanding of the general framework of the NCRPD
- Is aware of International Promising Practices in Access to Justice and Supported Decision Making for people with disabilities
- Has an understanding of some of the challenges experienced by people with disabilities in trying to exercise their Human Rights fully

#### Values

The Trainer

- Displays Acceptance and Respect for all people
- Believes that all people should be empowered to take action, make choices and exercise their Human Rights
- Is committed to working individually and collectively for the protection, promotion and realization of Human Rights for people with disabilities

#### Skills

The Trainer

- Can deliver all training modules in a competent and professional manner
- Can operate all technology required for the training activities
- Can use examples, reflective listening and feedback to encourage learner involvement.
- Has an awareness of some of the International practices and person centred tools that promote and facilitate Supported Decision Making for people with disabilities

#### Post training

Following Training Trainees will have

- An enhanced knowledge of the UNCRPD
- After the training trainers are able to understanding of the general framework of the UNCRPD
- An understanding of the differences between Substituted & Supported Decision Making
- An understanding of the concept of Reasonable Accommodation
- An appreciation of the different Stakeholders that may be involved in decision Making Processes and Access to Justice for people with disabilities
- An awareness of some of the International promising practices, communication supports & person centred tools, that promote and facilitate Supported Decision Making and Access to Justice for people with disabilities

b. **Conditions for joining/attending the training: potential supporters, therefore family members, peers and professionals.**

Number of persons in a group: No less than 5 and no more than 25 persons.

c. **Planned duration and structure of the training**

20 lessons [Theory + Practice]

Duration: 3 occasions (2.5 days)

Intensity (proposal):

**1 day [9:00 - 17:00]**

Welcome & Introductions

The United Nations Convention on the Rights of Persons with Disabilities and the European legal context

From substituted decision making to supported decision making

Access to justice

**2 day [9:00 - 17:00]**

Promising examples and practices

Communication with people with intellectual disabilities

Role of families and links with supporters of legal capacity

Personalizing support - How can we support persons with intellectual disabilities to have more control and choice in their everyday life?

**3 day [9:00 - 13:00]**

Changing the mindset

Evaluation

d. **Training methods**

Lecture with presentation, consultation, practical exercises, interactive methods.

- Basic principles:
  - Involvement of persons with intellectual disabilities and families
  - Framed by Human Rights (UNCPRD);
  - Involve practitioners of supported decision making (also international ones), where possible;
  - Involve and link social network of Persons with intellectual disabilities.
- Delivery:
  - Questions on UNCPRD (FAQs);
  - Co-delivery of Persons with intellectual disabilities with experience;

- Role plays and scenarios (real life);
- Case studies and problem solving;
- Interactive exercises and videos (e-learning).

e. **Technical requirements for the trainers:**

Training room with the necessary technological equipment, such as a laptop, projector, large TV screen for video multimedia review, internet, and flipchart board to provide visuals during the training.

f. **Evaluation:**

Filling the evaluation form at the end of the training. Afterward elaboration of the answers and evaluate the content. Please refer to the tool box for templates and suggestions about the evaluation.

## II. The United Nations Convention on the Rights of Persons with Disabilities and the European legal context

### OBJECTIVES OF THIS MODULE

- Understand the rights of persons with disabilities under the UNCRPD and how the provisions contained in the UNCRPD should be translated into practice.
- Understand the role of the European Union as party to the Convention.

### KEY MESSAGES OF THE MODULE

One of the hardest tasks facing the Convention on the Rights of Persons with Disabilities is bringing about a change in attitude and perceptions about disability. Mostly these are the result of prejudices that have consolidated over many years. Psychological barriers are the hardest to break down. The objective of the module is to create awareness and encourage discussion and reflection about disability in order to better understand the principles and the values of the human rights approach to disability.

#### **Tip for trainers:**

*Start with a brainstorming activity on the meaning of "disability" to participants*

*Show the following video to set the framework (you may decide to split the video in two parts and show the second part after the end of Section 1 of this module):*

<https://www.youtube.com/watch?v=iLaZX6ib6Tk>

### LESSON PLAN OF THE MODULE

**Recommended length: 1h 45 minutes + 15 minutes evaluation**

Item	Tool	Timeframe
Introduction	Brainstorming	10 min
The UN CRPD	Presentation	10 min.
The UN CRPD	Video (1st part)	4 min.
The shift of paradigm from medical to human rights approach	Presentation	15 min.
	Video (2nd part)	6 min.
	Power walk exercise	25 min.
Principles of the UN CRPD	Presentation	5 min.
The state of play and the way forward	Presentation	10 min
The European legal context	Presentation	10 min
Conclusions	Presentation	10 in

## 1. THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

### a. Introduction and structure of the convention

At the beginning of the 20<sup>th</sup> century institutionalisation and mistreatment of persons with disabilities was still the norm.

Abuse of persons with disabilities during the World Wars and the huge amount of veterans that came home with disabilities brought momentum to discuss challenges and changes ahead for the disability movement. At the time the approach to disability was mainly ruled by a medical model, which was responsible for splitting society in two: one for persons with disabilities and the other one for those without a disability.

This mind-set has been deeply rooted in society, in people's way of thinking on disability and in the way life was built around for those having a disability. In concrete terms it led to the exclusion of disabled persons, being denied access to mainstream services and being condemned to enjoy fewer rights and opportunities.

The needs, requirements and ultimately the rights of persons with disabilities have evolved progressively at international level until their proclamation in a Convention which entered into force in 2008: the United Nations Convention on the Rights of Persons with Disabilities - hereafter referred to as the "Convention" or the 'CRPD.' The CRPD is the definitive international framework setting out the rights of persons with disabilities and it has been ratified by most of the countries of the European Union and the European Union itself in 2010.

The Convention introduced a **holistic and integrated human rights approach** to address social and economic inequalities faced by persons with disabilities. It clearly acknowledges that societal barriers and prejudices are themselves disabling. Therefore society is required to adapt to persons - and not the other way around - according to their specific individual needs and by putting in place structures and measures to facilitate access of persons with disabilities into society. Individualized support, personalized planning and empowerment of individuals are elements required to be part not only of the outcomes of policies, but should be carefully built into all processes and policy instruments.

The CRPD does not introduce new rights for persons with disabilities; its aim is to apply the principle of non-discrimination to every human right and in every context of human beings' existence. The CRPD is **legally binding on States which have ratified it** and therefore its articles are paving the way to future policy developments in the disability sector.

The requirements set by the Convention are challenging, as they demand consistent and substantial changes in the way the needs of persons with disabilities should be addressed and met. As a consequence, organizations that are providing services for persons with disabilities should be (re)structured in a way that is compliant with the CRPD principles. This may require substantial changes and the transition leading to services that adhere to the human rights model of disability may not be smooth and easy.

### b. Structure of the Convention

The Convention comprises 50 Articles:

- Article 1 "Purpose": it includes the definition of "persons with disabilities": *Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*
- Article 2 "Definitions"

- Article 3 "General principles"
- Article 4 "General obligations"
- Article 5 "Equality and non-discrimination"
- Article 6 – 30 concern specific categories and/or areas of life
- Article 31 "Statistics and data collection"
- Article 32 "International cooperation"
- Article 33 – 39 concern monitoring and implementation of the Convention
- Article 40 – 50 deal with legal procedures and entry into force of the Convention.

More broadly the implementation of the CRPD by State Parties is monitored by the **Committee on the Rights of Persons with Disabilities**. It comprises a body of independent human rights experts elected every two years. State Parties are required to submit regular reports to the Committee on the progress they have made in including the provisions of the Convention in their legislation as well as in how they are implementing them in the daily lives of persons with disabilities.

### c. **The shift of paradigm from a medical to a human rights model**

Since the adoption of the CRPD by Member States and the European Union a **paradigm shift** on disability has occurred.

There has been a movement away from a medically oriented model of care, where the person with a disability is viewed as a passive receiver of care, or worse, as a person whose disability needs to be "cured", towards a **human rights model**, where individuals are supported to become active citizens of their communities.

In particular, the Convention marks an important step in three unfolding key changes in the field of human rights for persons with disabilities<sup>3</sup>:

- a shift from "objective needs to subjective rights", which entails a gradual development from policies dealing with "objective needs" to policies aiming at the enjoyment of "subjective rights".
- a change of mindset from paternalistic to interactive ethics. The Convention displays a gradual replacement of a top-down ethic, which treats persons with disabilities as passive recipients of care, by an interactive ethic, which involves persons with disabilities in decision-making and restores their self-determination.
- the demand to look beyond material conditions and focus also on the empowerment of the individual with a gradual development from an emphasis on providing shelter, food and medical care to a growing emphasis on individual choice, autonomy and participation.

Acceptance and implementation of the CRPD provisions constitute the next steps after its ratification. The role of civil society, civil servants and State authorities is to promote the shift of paradigm required by the Convention and support society in further developing its understanding and correct implementation.

For service providers the requirements set out in the CRPD call for a re-shaping of how services are provided, the development of new services not currently available to meet new and changing needs and/or the integration in services of a person centred, inclusive, participative and individualised approach, adopting the new human rights model of disability.

### d. **The key principles of the Convention**

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<sup>3</sup>Quinn G, Degener T 2002. Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability. United Nations, New York and Geneva

While the Convention elaborates a number of issues concerning different areas of life, some concepts underpin its rationale and are therefore key in interpreting the text as they set the basis for building a society free of stigma and hence discrimination. In this regard the Convention should be read and understood as a whole document since the rights and the obligations within it are interlinked and give an insight into the correct implementation of all articles.

The guiding principles of the Convention - as per Article 3 - are:

- a) Respect for inherent dignity, individual **autonomy** including the freedom to make one's own choices, and independence of persons
- b) **Non-discrimination**. This includes the right to **reasonable accommodation** which requires States to ensure adaptations of the environment to enjoy and exercise rights on an equal basis with others.
- c) Full and effective **participation and inclusion** in society. These concepts are linked to the need for society to accommodate and adapt to the persons needs and wishes without restrictions or limitations of any kind.
- d) **Equality** of opportunity.
- e) **Accessibility**, to be understood as beyond the removal of architectural barriers and including access to communication in multiple formats (e.g. Braille, easy to read, sign language, etc.) as well as to human support.
- f) **Equality between men and women**.
- g) Respect for the evolving capacities of children with disabilities and respect for the **right of children** with disabilities to preserve their identities.

All concepts should be understood in a very broad meaning to allow persons with disabilities to enjoy equality of treatment with their non-disabled peers, overcoming the barriers deriving from their disability.

The above concepts apply equally to people and social services which are highly challenged as they need to be (re)structured in a way that is in line with the principles of the Convention. Like society, most services have been organized so as to provide for assistance and care under the medical support-based approach, which limited freedom of choice and responsibilities for users and had a protective approach - rather than an empowerment-oriented attitude promoted with the Convention - which, with the best possible intentions, resulted in the exclusion of people with disabilities from the rest of society.

Society must (re)organize services for a consistent part of the population, adapt existing structures, create new ones and put into place the right support mechanisms for all. This implies a huge effort both at financial level, as well as in terms of human resources (e.g. re-training of staff under the CRPD principles, etc.), but significantly the need to recognize that part of the established services are not acceptable according to the standards set out in the Convention.

### ***Tip for trainers***

*Use the "Power walk exercise" to show how the reality is very different from the theoretical frameworks.*

## **2. THE STATE OF PLAY AND THE WAY FORWARD**

The shift of paradigm challenges society as a whole as rights have to be understood according to new interpretations. This means on one side that awareness has to be raised in order to understand correctly the principles behind every article, and on the other side States have to comply with these rights, implementing UNCRPD correctly. This includes the following steps:

- aligning all legislation to the UNCRPD obligations;
- setting up appropriate support schemes and services and readapting existing ones according to the international standards set by the Convention;
- raising awareness in society on the rights of persons with disabilities in order to promote their full participation.

Managing the transition towards a social model of disability contains many challenges. Careful planning is required to avoid unintended harmful consequences and to ensure that the outcomes are fully in line with the Convention. Person-centred approaches meeting the specific needs of persons with disabilities should be designed and implemented in a way that promotes participation and inclusion and does not deprive them of choice and control in their own life.

### 3. THE EUROPEAN LEGAL CONTEXT

The European Union ratified the CRPD in 2010 and became a party to the Convention. By doing this the EU committed to comply with the CRPD obligations and requirements in the areas which fall under EU legislative competence. As “regional integration organization<sup>4</sup>” the competences of the EU in regards to CRPD implementation are limited from a legislative point of view. However, in areas concerning awareness raising, the EU can act as a very important role model to set standards at European and national level.

In Europe the main instrument to implement the CRPD at European level is the European Disability Strategy 2010-2020<sup>5</sup> (EDS). The EDS is meant as an overarching strategy for the EU to mainstream disability issues across all European policies.

With regard to Articles 12 the EU underlined in the “Report on the implementation of the CRPD by the EU<sup>6</sup>” that it “has no competence to regulate the question of legal capacity; this rests with the Member States. As regards Article 13 the EU “shares competences with the Member States in the area of freedom, security and justice which is relevant for the implementation of Article 13 of the CRPD.”

The limited competence to legislate on legal capacity and access to justice does not allow the EU to have a direct role in changing legislation that is not in line with the CRPD and that does not promote supported decision making mechanisms of support, however, the EU can support the latter through awareness raising activities.

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<sup>4</sup> A “Regional integration organization” is defined in Article 44 of the UN CRPD as an “organization constituted by sovereign States of a given region, to which its member States have transferred competence in respect of matters governed by the present Convention. Such organizations shall declare, in their instruments of formal confirmation or accession, the extent of their competence with respect to matters governed by the present Convention. Subsequently, they shall inform the depositary of any substantial modification in the extent of their competence.”

<sup>5</sup>European Disability Strategy 2010-2020:A Renewed Commitment to a Barrier-Free Europe  
<http://ec.europa.eu/social/BlobServlet?docId=6284&langId=en>

<sup>6</sup>European Union, (SWD (2014) 182)



In Europe two other bodies promote and protect human rights for European citizens: the Council of Europe and the European Court of Human Rights, which are based in Strasbourg:

- The Council of Europe is a regional intergovernmental organization which promotes human rights, democracy, and the rule of law in its 47 member states. The Council of Europe is separate from the 28-nation European Union, and unlike the European Union, it cannot make binding laws.
- The European Court of Human Rights is a supranational or international court established by the European Convention on Human Rights. It hears applications alleging that a contracting state has breached one or more of the human rights provisions concerning civil and political rights set out in the Convention and its protocols.

As an example, in 2012, in the case of Mr Stanev against Bulgaria, the European Court of Human Rights found that Mr Stanev's placement in the social care institution, against his will and for an independent period of time, on the order of a government employee, meant that Mr Stanev had clearly experienced a deprivation of his liberty. The Court ordered that Mr Stanev should be asked whether he wished to remain in the social care institution and if not a re-examination of his situation should be carried out. This example shows how in its judgments the European Court of Human Rights may provide indications on how to support the promotion of human rights.

#### 4. EXERCISES

##### **Power walk.**

*This exercise simulates a community in development where everyone starts off as equals, but by the end of the exercise, everyone will have experienced very different outcomes based on the process of development and the individual abilities to claim his own rights. The objective of this exercise is to highlight the persistence of inequalities in society even though human rights are the same for everyone.*

[http://portal.unesco.org/shs/en/files/8312/11212770881RP-June-S\\_5.pdf/RP-June-S+5.pdf](http://portal.unesco.org/shs/en/files/8312/11212770881RP-June-S_5.pdf/RP-June-S+5.pdf)

##### **Video**

<https://www.youtube.com/watch?v=uUwHIbQFszU>

This video explains in brief how the change of mindset provided by the Convention and the set of rights persons with disabilities are entitled to.

##### **Exercises**

Power walk.

This exercise simulates a community in development where everyone starts off as equals, but by the end of the exercise, everyone will have experienced very different outcomes based on the process of development and the individual abilities to claim his own rights.

[http://portal.unesco.org/shs/en/files/8312/11212770881RP-June-S\\_5.pdf/RP-June-S+5.pdf](http://portal.unesco.org/shs/en/files/8312/11212770881RP-June-S_5.pdf/RP-June-S+5.pdf)

## 5. BIBLIOGRAPHY/RESOURCES

European Union Agency for Fundamental Rights 2013. Legal capacity of persons with intellectual disabilities and persons with mental health problems

OHCHR Training Package on the UNCRPD

<http://www.ohchr.org/EN/HRBodies/UNCRPD/Pages/OptionalProtocolRightsPersonsWithDisabilities.aspx>

Quinn G, Degener T 2002. Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability. United Nations, New York and Geneva

United Nations Convention for Rights of Persons with Disabilities:

<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

Other languages and formats are available here:

<http://www.un.org/disabilities/default.asp?id=150>

United Nations Enable website: <http://www.un.org/disabilities/index.asp>

### III. From substituted decision making to supported decision making

#### OBJECTIVES OF THIS MODULE

- Understand the legal framework of supported decision-making under the UNCRPD, giving its historical and theoretical context.
- Introduce principles and guidelines for the practical functioning of supported decision-making.

#### KEY MESSAGES OF THE MODULE

People with intellectual disabilities have legal capacity like all people do. It is possible, however, like all people, that their decision-making ability varies depending on social, environmental and personal factors.

This should be addressed by using supported decision-making, which leaves the individual autonomy of the mentally disabled person unchanged and ensures the person retains control over his own life.

Supported decision making primarily differs from substitute decision making in that the decision is made by the concerned person him/herself,, with support of others, which is voluntary and is based on trust.

It is the supported person's intentions and aspirations that matter in the course of supporting, and not his "objective" interest.

#### LESSON PLAN OF THE MODULE

Recommended length: 2 hours (120 min)

Item	Tool	Timeframe
Introduction	Presentation, video *	15 min.
Definitions	Presentation	10 min.
Exercise (draw)	Flip chart paper*	15 min.
The principles of supported decision making	Presentation, example*	10 min.
Group work examining case studies (will and preference vs. best interest)	Group work, discussion *	20 min.
Good practice in supported decision making	Presentation, examples, discussion *	20 min.
Improving autonomy and independence with special regard to persons with complex needs	Presentation, examples, discussion *	10 min.
Conclusion	Presentation, examples, videos, Presentation, discussion*	20 min.

\* Co-training by persons with intellectual disabilities is encouraged.

### **Tips for the trainers**

*There are several case examples that you may use for role play, discussion or other interactive activity based on your national legal background of supported decision making.*

## **1. INTRODUCTION**

Article 12 of the UNCRPD has strong ties with certain **general principles** of the UNCRPD, such as respect for human dignity, individual autonomy, non-discrimination, full and effective participation and inclusion in society.

The importance of Article 12's insistence of the recognition of legal capacity of people with disabilities must be understood in the context of the historical treatment of people with disabilities and their presumed inability to make decisions about their lives. The UNCRPD assumes that adults without disabilities are able to engage in all aspects of life-deciding where to live, whom to have relationships with, management of one's financial affairs, etc. on an autonomous basis. The lived experience for adults with disabilities has been and continues to be quite different. States have assumed that the mere status of having an intellectual disability provides a sufficient basis to presume that the individual is unable to participate fully and autonomously in society, in other words, that the individual lacks the legal capacity to exercise his or her rights. In this mode of thinking, people with disabilities need protection, not rights. Guardianship is the primary mechanism through which states have provided this protection; but at the expense of the individual's human rights. It is a mechanism that, the UNCRPD, and Article 12, seeks to abolish.

Article 12 of the UNCRPD anchors **equal recognition of persons with disabilities before the law**. It says that States Parties shall recognize that persons with disabilities enjoy legal capacity (definition: see sec. V.2.) on an equal basis with others in all aspects of life. The UNCRPD states that any legal regulation which permits the restriction of legal capacity on the basis of disability must be abolished. Article 12 requires that, consistent with the human rights model of disability, states must provide access for persons with disabilities to the support they may require in exercising their legal capacity. Persons with disabilities have to be granted all reasonable support to act autonomously on an equal basis with others.

## **2. DEFINITIONS**

**Legal capacity** has two different levels: **capacity for rights** and **capacity to act**. The former means that an individual may have rights and legal duties. International human rights instruments guarantee the capacity for rights for all people, and this is a key element of participation in society.

Capacity to act has a narrower meaning: that a person has the power to create rights and obligations for him/her-self or for others. Thus capacity to act is the basic condition for autonomous acting in the field of law, which is a key element of participation in society. The concept of legal capacity involves both capacity for rights and capacity to act.

International human rights instruments guarantee the capacity for rights for all born people. However, capacity to act is traditionally not ensured for everyone at national level. Minors and **certain groups of persons with disabilities, especially with intellectual or psycho-social disabilities are usually denied full capacity to act, but the UNCRPD is clear that this must change.**

Restrictions on legal capacity are typically achieved by the legal instruments of **substituted decision-making**. Under different national laws, legal instruments for substituted decision-making take different forms and are called by various names (e.g. guardianship, conservatorship, trusteeship etc.). Substituted decision-making may be **plenary** or **partial**, whether it covers all the legal affairs of the person or only a part of them. Legal capacity may be **denied**, for example if the substitute decision-maker makes the decisions on behalf of the person on his/her own; or may be **restricted**, if the guardian and the person have joint decision-making rights. **Common features** of substituted decision-making are as follows:

- legal capacity is removed from a person, even if this is just in respect of a single decision
- a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his/her will
- any decision made by a substitute decision-maker is based on what is believed to be in the 'objective best interests' of the person concerned, the supported person, as opposed to being based on the person's own will and preferences.

**Supported decision-making can be defined as follows:**

- It does not affect legal capacity: the individual makes his/her decisions and legal statements on his/her own
- the supporter is appointed by the supported person, or at least with his/her consent
- the supported person can follow his/her own will or preferences, even if the outcome is unreasonable, risky or in conflict with his/her objective 'best interest'.

**Tips for the trainers**

*Free drawing exercise to encourage associations (teamwork)*

*The objective of teamwork: To challenge the participants' creativity by discussing what it means for a person to decide independently and to be supported in this independence. The exercise improves the empathy skills of the participants. The objective of the exercise is to encourage participants to interpret various situations and immerse in them by applying visual tools.*

*Divide the participants into small groups (3-4 people). Their task is to make a drawing with the title "supported decision-making". Give participants instructions as to concentrate on the title of the task and try to capture and visually express the essence of supported decision-making, for which they can use symbols freely (e.g.: birds, fences, bridges, etc.) The completed pictures will be displayed in the classroom and will be viewed together. The groups will not have to explain what they were drawing and why. After viewing, provide an opportunity to the participants to discuss their experience in an informal conversation.*

**3. THE PRINCIPLES OF SUPPORTED DECISION-MAKING**

Legal instruments like the supported decision-making model existed in a few national laws (e.g. Sweden, Germany, Canada) prior to the UNCRPD, and are likely to become more widespread as a result of the Convention. As the UNCRPD does not provide basic criteria for Supported decision-making, they are likely to take various forms. The common characteristics of Supported decision-making are as follows.

a. **Relationship built on respect of rights**

Supported decision-making relies on a **trust-based relationship** between the supporter and the supported person sometimes based upon a formal agreement. This can be done through a deed or before a court. Supporters are often friends or family members. In some situations, a **professional can be appointed as a supporter, but** only if the supported person agrees, and where conflicts of interest are minimised.

b. **Supported decision-making is based on individual will and preferences**

The supporter has to assist the supported person to make the relevant decision according to his/her own will and preferences and not what is believed to fit his/her objective best interest in the opinion of the supporter or anyone else. Supported decision-making is therefore appropriate **to maximize someone's individual autonomy**.

**Example:** An 18-year-old young man with intellectual disabilities has finished his compulsory studies and may now either work or attend some form of vocational training. In the opinion of his supporter the supported person would be wise to undertake further study (that is in his/her objective best interest). However, the man prefers to work (that is his will and preferences). On the basis of supported decision-making the supporter should respect the supported person's will and preferences and help him find his own way of life.

**Tips for the trainers**

*The objective of the teamwork: To promote that it is the supported person's intention and aspiration that matter when it comes to supported-decision making, and not their "objective" best interest. The practice brings situations which show the collision of these two competing viewpoints clearly. Dealing with these helps the participants to act in the right way as a supporter in future cases.*

*Group work examining case studies of some complexities in understanding Will & Preference vs Best interest when supporting people to make decisions*

*In pairs, review Case Studies and reflect back to larger group on challenges in decision making process.*

Sample story 1

**Mary** is a 45 year old woman. She has Downs Syndrome and a moderate learning disability. She lives in a supported community house. She works in a local shop and earns €100 a week in addition to her Disability Allowance. Mary smokes up to 20 cigarettes a day, and has been a smoker for 25 years. She refuses to go for a check-up with any doctor, and has refused all offers of support to cut down on her smoking. She is often out of breath, and has a bad cough in the morning. Her father died at 50 of a heart attack. Money is not an issue for Mary, she is happy once she has enough for her cigarettes.

Mary says doctors have no right to examine her against her will, and she has a right to spend her money on what she wants, and smoke her own cigarettes.

Sample story 2

**John** is 25 years old; he has a mild learning disability and autism. He is non-verbal. He attends a day service. Since his parents death five years ago John has lived with his only sibling, his brother, who is his advocate, and does not have a disability. Both brothers are clinically obese. John tells staff that at home they eat mainly fast food, drink fizzy drinks,

and beer, while playing video games every evening. John's staff support him to attend annual medical check-ups. His GP has expressed his concern to John and his support staff that John's lifestyle could lead to him developing diabetes, heart problems, and other issues related to his weight. Neither John nor his brother see the need to manage their weight, or change their lifestyle. John's brother says no one has the right to tell him what John should be eating or drinking, or how they should manage their lives.

### Sample story 3

**Jack** lives alone, with drop in support from a local disability organisation. He gets a Disability Allowance, and he earns €180 a week at work in a local garage, where he is supported by a job coach. He enjoys gambling, and often has not got enough money to pay his rent or buy food. He has refused all offers of help with money management, and he recently borrowed money at high interest from a local money lender to pay some bills. He says his money is his business. His community support staff and job coach are concerned that his gambling is more than a pastime, and may be an addiction. They worry that he will get into so much debt and could lose his home. Jack says he has a right to do as he chooses with his money.

### Sample story 4

**Kate** lives in a shared community house. She has a mild learning disability, and is bi-polar. Kate works part time in a local coffee shop. She can travel independently. She enjoys going dancing. She sometimes goes to night clubs in town, and comes home late. Kate has sometimes taken lifts home from men the staff do not know. Her freedom of movement is very important to her. Kate says she is careful, and only takes lifts from people who are friendly, and have danced with her during the evening. Staff are concerned that she is naïve and vulnerable, and should not be allowed to go to nightclubs alone. Kate says she has never had a problem, so she believes this proves that she can look after herself, and she has a right to have freedom to go where she wants, and choose her own friends.

## c. **Voluntary decision**

**Supported decision-making always takes place voluntarily.** The supported persons should choose who they want to support them and agree where and when that support will be needed. Often there will be an informal agreement to confirm these arrangements.

In some countries supported decision-making may be a more formal arrangement with the supporter having **a recognized legal status**. This can entitle the supporter to attend decision-making meetings, request information, and consult with other persons and/or organisations, interested in any decision. Such legal status can give greater credibility to the supporter and the supported decision-making model.

## d. **Self-determination, independence and autonomy, active participation and involvement**

Like everyone, persons with intellectual disabilities have legal capacity. Any difficulties in exercising this capacity should not be addressed by a restriction of legal capacity, but through providing support, so that the person can make decisions. This solution does not affect **individual autonomy**, i. e. self-determination in all fields of life.

Western national laws are typically based on a **liberal concept of autonomy**. The ideal human being is a free, independent person, who is able to recognize and execute his/her will and interests, who anticipates the consequences of his/her conduct, and can take responsibility for it. This approach has been critiqued in recent years by those who favour a more **inter-dependent or relational account of autonomy**, which recognizes that we all rely on others for support to achieve full self-determination.

#### 4. CHALLENGES IN SUPPORTED DECISION-MAKING

##### a. Type and intensity of support

The principle of **reasonable accommodation** must be taken into account in the course of supported decision-making. The individual is entitled to the appropriate kind and quality of support for independent decision-making, unless it puts a disproportionate burden on the person providing the support. Accommodation should be flexibly adjusted to the needs of the supported person.

**Support can be linked to more steps in the process of decision-making**, including:

- recognition of the need for a decision
- motivation for decision-making
- collecting of information on any decision options
- consideration and prioritization of necessary information
- making a choice from options
- declaration or communication of the decision.

**Supportive action can take various forms:** personal presence, advising, consulting with others concerned about the decision, exploring or translation of documents, technical assistance (e.g. using IT services, providing personal transportation) etc. In compliance with the requirement of reasonable accommodation, all assistance that is provided should not represent a disproportionate burden on the supporter.

**Example:** Adriana, a supported person with cognitive and mobility disabilities, would like to spend her holiday abroad. She may need the supporter to help use the internet to so that she can find a good holiday that suits her at a good price. Asking the supporter to accompany the supported person on the holiday might impose a disproportionate burden, depending on the circumstances.

**Supporter tasks can also be influenced by national legal regulations.** For example the supporter role may be shared or the supporter may have a duty to cooperate with other supporters.

##### b. Risk management

How should we act when it is not practicable to determine the person's will and preferences? The purpose of supported decision-making is to help the supported person to make decisions according to his/her will and preferences. This decision may happen not to correspond to his/her objective 'best interests'. Furthermore it may not be the same decision as he/she would make without support. First and foremost the supporter must have a deep and thorough interest in discovering the **real will and preferences of the supported person**. The support has to be directed to implement this, and not the preferences of the supporter.



**Example:** Alex is a supported person who has several problems with his boss. Alex's supporter, Brandon believes that Alex should quit his job, but Alex definitely wants to stay. Further probing by Brandon (supporter) reveals that Alex has good reasons to stay. Alex is interested in another job in the same company and he has been told informally that he can have the new job. Alex lacks confidence about how to make this change. While Brandon (supporter) still has reservations about the wisdom of Alex staying with the company, he must help Alex fulfil his preferences.

It is important to note that sometimes **will and preferences can be a question of interpretation.**

**Example:** After several months searching, a person with intellectual disabilities finds his dream home. Verbally he agrees a purchase price with the owner. On the morning of the scheduled date to sign the contract he changes his mind. He explains that he had a nightmare about the new house. In this case it is extremely important to examine this decision thoroughly to discover the individual's will and preferences.

Sometimes we all take risky decisions, if we can achieve a certain goal only at the price of some possible harm. Human freedom involves the opportunity to exercise '**dignity of risk**'. Persons with intellectual disabilities should similarly not be forced to choose always the least risky option in a decision-making situation. Supporters are supposed to help them develop the supported person's risk-management abilities (to explore the risks and eventually to live with them). Supporters are often worried about letting the supported person do something risky lest the supporter be found at fault for letting the risk happen. It is a complex legal and societal problem to judge where to apportion liability in such situations.

### c. **Undue Influence**

Several national laws include the concept of **undue influence** or something similar. This nullifies a decision if one of the parties entering into it were bullied or subject to undue influence by the other party.

People with intellectual disabilities may be **particularly vulnerable** to undue influence. Like all of us, they are exposed to the risk of being abused by others, who, by using emotional pressure, real or putative, can withhold or distort relevant information so that the person with intellectual disabilities makes unwise or personally damaging decisions.

The States Parties should **set legal rules** to protect potential victims of undue influence. Unfortunately these contracts may be held void just subsequently, when the damaging action has already occurred.

Supported decision-making **may be an effective tool to prevent undue influence.** It depends however on the supported person having a trusting relationship with the supporter and feeling confident to turn to the supporter in advance of whenever he/she needs help with a decision. Laws regulating supported decision-making must also include safeguards to prevent supporters from unduly influencing those they support.

The supporter should make sure that all relevant information is available before any decisions are taken, so that the supported person can readily weigh up the alternatives and can decide freely, according to his/her own will and preferences.

**Example:** A woman with an intellectual disability attends a product marketing show about a high performance, expensive vacuum cleaner. The woman had asked her sister and supporter to come along to the show in case she might want to make a decision about buying the cleaner. At the end of the show the salesperson asks the woman whether she has been convinced and had decided to buy the cleaner. The woman asks her sister to answer. In this situation the correct conduct for the supporter is not to decide instead of the supported person or influence her to make a decision, but to consider with the woman all the relevant information (e.g. cleaning needs, whether the woman can afford the cleaner etc.), and to encourage the woman to make her own decision.

#### d. **Measures related to financial affairs**

Section 5 of Article 12 of the UNCRPD requires States Parties to **take all appropriate and effective measures to protect persons with intellectual disabilities from financial abuse.**

A supporter of a person with intellectual disabilities **must not make arbitrary decisions** about the supported person's **property**. He/she has to make sure that the financial decisions of the supported person fully reflect her/his genuine will and preferences. If the supported person empowers the supporter to act in financial affairs instead of him/her, the supporter must take all efforts to preserve the value of the property, and to do it lawfully, according to the will of the supported person.

If the supported person has a family, **his/her financial decisions may affect the family property**. The supporter should draw the supported persons attention to this issue, so as to avoid foreseeable but unwanted family conflicts arising from unreasonable financial decisions.

**Example:** A man with an intellectual disability has a sister who is a supporter. He falls in love with a young female shop assistant, and wants to marry her. The supporter suspects that the woman is only interested in marriage to get her brother's money. The supporter and supported person meet on several occasions to discuss the marriage plans. Eventually, the man decides to get married. Shortly after the wedding the wife moves away, with all his money. The supporter can discuss with the man whether he wants to pursue legal remedies to retrieve his money.

### **5. IMPROVING AUTONOMY AND INDEPENDENCE WITH SPECIAL REGARD TO PERSONS WITH COMPLEX NEEDS**

Supported decision-making is more than a legal instrument and the position of the supporter is more than a legally defined role. **The essence of supported decision-making is an attitude towards the supported person** which aims to **maximize his/her autonomy**. Legal norms/rules, if they exist, determine only the framework of supported decision-making.

Crucial to the successful practice of the supported decision-making model is the supporter's ability to be creative and proactive. The supporter cannot always rely on the supported person to express their wishes because a limited decision-making capacity may hinder the ability of the person to recognize and articulate these. The supporter can share his/her own ideas about any decision to be taken, if requested to do so by the supported person, but cannot push the supported person to accept his/her ideas.

**Example:** A woman suffers from chronic stomach problems. Her supporter should, in the absence of any expressed request from her, take the woman through the different treatment options. The supporter should not push her to opt for one of the suggested solutions 'in her best interest'.

The supporter should also keep the importance of **subsidiarity in mind**, particularly where supporting people with high support needs. The supporter has to distinguish between those situations where their assistance is essential and those where the supported person wishes to make an autonomous decision. Thus, the supported decision-making may be **an effective instrument for capacity-building and enhancing decision-making skills**.

**Example:** A supported person, living in a big city, wants to attend aerobic classes, but does not know where they take place or what she needs to do. The woman calls her supporter for help. The supporter reminds her that she is familiar with internet use, and that using the internet could be a good way to find an appropriate fitness class.

## 6. BIBLIOGRAPHY AND RESOURCES

Committee on the Rights of Persons with Disabilities, General Comment on Article 12 - on Equal Recognition before the Law CRPD/C/GC/1 - Available in 6 languages on : [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en)

Dhanda, A., Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future, *Syracuse Journal of International Law and Com.*, vol. 34, 2007, 429-462

Gombos, G., Hoffmann, I., Könczei, Gy., Nagy, Z., Szabó, Gy., *A támogatott döntéshozatal elmélete és gyakorlata*, ELTE BGGYK, Budapest, 2009 (Hungarian language)

Glen, K. B., Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond, *Columbia Human Rights Law Review*, vol. 44., 2012, 93-168

M.Browning, C. Bigby, J.Douglas; Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice Research and Practice in Intellectual and Developmental Disabilities, 2014 Vol. 1, No. 1, 34-45 ([http://supporteddecisionmaking.org/sites/default/files/browning\\_et\\_al\\_2014.pdf](http://supporteddecisionmaking.org/sites/default/files/browning_et_al_2014.pdf))

Quinn, G., Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 UNCRPD (Paper presented at Conference on Disability and Legal Capacity under the UNCRPD, Harvard Law School, Boston, 20 February 2010)

**Videos:**

Gabor Gombos speaks about Articles 12 and 13 UNCRPD at the 7<sup>th</sup> International Disability Law Summer School, NUI Galway:  
[https://m.youtube.com/watch?list=PLvKS9kpe3SYPiGcT5eNPRFWnzDq1fQxju&v=wxLZ1pm\\_Y4w](https://m.youtube.com/watch?list=PLvKS9kpe3SYPiGcT5eNPRFWnzDq1fQxju&v=wxLZ1pm_Y4w)

Justice for Jenny Hatch Project: <https://www.youtube.com/watch?v=iKpIR1MpCkE>

Cher Nicholson on the South Australian Supported Decision-Making Trial:  
<http://www.youtube.com/watch?v=xwg5yQ-WoCY>

Inclusion International video on 'My Right to Decide' <http://inclusion-international.org/right-decide-matters-mia/>

**Research projects on legal capacity and supported decision-making:**

VOICES [www.ercvoices.com](http://www.ercvoices.com)

PERSON [www.eu-person.com](http://www.eu-person.com)

Inclusion International 'Right to Decide' <http://inclusion-international.org/category/priorities/legal-capacity/>

Examples of supported decision-making around Europe: <http://www.right-to-decide.eu>

***Tips for trainers***

*Please include possible resources at national level*

## IV. Access to justice

### OBJECTIVES OF THIS MODULE

- Understand the meaning of the right to access to justice for persons with intellectual disabilities in the context of the UNCRPD and the international human rights framework.
- Understand the role of supporters in securing access to justice.

### KEY MESSAGES OF THE MODULE

The main forum for enforcement of rights in all countries is the administration of justice, the core of which is the judicial system.

Everyone should have the opportunity of delegating the enforcement of their rights to a court that renders judgment impartially, independently and lawfully.

The right of persons with disabilities to effective right enforcement, that is, their access to justice, is laid down in the UNCRPD.

In order to make justice more accessible we have to overcome the legal obstacles on the one hand (e.g.: having no legal standing, legal barriers of participating as a witness) and the practical obstacles on the other hand (physical barriers of appearance in front of the court, communicational barriers of making a declaration, the obstacles of orientation, the lack of consideration of special needs).

### LESSON PLAN OF THE MODULE

Recommended length: 2 hours (120 min)

Item	Tool	Timeframe
Introduction	Presentation *	10 min.
Defining access to justice and reasonable accommodation	Presentation *	10 min.
Securing rights through access to justice	Presentation (10 min), discussion (10 min)*	20 min.
Article 13 in the context of the UNCRPD and human rights	Presentation (5 min) discussion (5 min)*	10 min.
Making justice accessible	Presentation (5min), brainstorming (10 min), discussion (5min)*	20 min.
Promoting access through procedural rights /promotion proceeding as party	Presentation (5 min), role play in pairs (10 min), discussion (5 min)*	20 min.
Promoting access through procedural rights /promotion proceeding as witness	Presentation +discussion*	10 min.
Making the facilities of justice system accessible	Presentation +discussion*	10 min.
Conclusion	Video (Dee's place), discussion*	10 min

\* Co-training by persons with intellectual disabilities is encouraged.

## 1. DEFINING ACCESS TO JUSTICE AND REASONABLE ACCOMMODATION

**'Access to justice'** is a 'broad concept, encompassing people's effective access to the systems, procedures, information, and locations used in the administration of justice. Persons who feel wronged or mistreated in some way usually turn to their country's justice system. In addition, persons may be called upon to participate in the justice system, for example, as witnesses or as jurors in a trial. Unfortunately, persons with disabilities have often been denied fair and equal treatment before courts, tribunals, and other bodies that make up the justice system in their country because they have faced barriers to access. Such barriers not only limit the ability of persons with disabilities to use the justice system, they also limit their contribution to the administration of justice.'

**'Reasonable accommodation'** refers to necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms. According to the terms of the UNCRPD, 'discrimination on the basis of disability' (...) includes all forms of discrimination, including denial of reasonable accommodation.'

### Overview of Article 5 of the Convention (equality and non-discrimination)

Equality is one of the general principles of the UNCRPD (Article 3; see sec. VII.2.). The principle of equality does not mean that each person shall be treated in an identical way. Equality, in the light of justice, has two aspects: those ones, who are in identical situations, have to be treated identically, while those ones, who are in different situations, have to be treated respectively differentially. The Article 5 of the UNCRPD reflects both aspects. Where there is no difference between persons with intellectual disabilities and able people, it is impermissible to discriminate against the former ones (see Article 5 (2)). However, where there is a real difference between persons with intellectual disabilities and able ones, positive action to ensure substantive equality for persons with intellectual disabilities is justified. Clause 3 covers the concept of reasonable accommodation, stating, in compliance with the social model of disability, that in any procedures, practices or services reasonable adjustments must be made to make them accessible to persons with intellectual disabilities, so long as they do not impose a disproportionate burden on providers. Specific arrangements (positive actions) are encouraged to mitigate or remove social barriers in Clause 4.

## 2. SECURING RIGHTS THROUGH ACCESS TO JUSTICE

Assertions of human rights remain empty declarations without effective instruments for implementation. The main mechanism for law enforcement in every state is the justice system, represented by courts and related public authorities (police, public prosecutor's office, penal institutions, organs of civil execution etc.). The **basic mission of justice** is to safeguard and enforce the rights of citizens.

An essential element of a democratic societal life, in which human rights are respected, is that all citizens have equal access to the system of justice.

### ***Tips for the trainers***

*Objective of the exercise: to attune the participants through their own experiences to the possible practical and other barriers that could hinder the enforcement of rights and access to the law and to what reasons could lead to someone not being able to apply for the*

*appropriate legal remedies in the case of violation of his rights (e.g.: lack of information, fear of sanction, etc.)*

*Discussion question: Has anyone had the experience of having a right to something, but being unable to receive or enjoy it? What were the barriers in your way?*

*Collect the experiences of the participants on the flipchart board and analyze them collectively.*

### 3. ARTICLE 13 IN THE CONTEXT OF THE UNCRPD AND HUMAN RIGHTS

Article 12 of the UNCRPD on legal capacity is often characterized as a key part of the convention. This article reaffirms the equality of persons with intellectual disabilities before the law, and, as an element of this, that they can exercise their legal capacity on an equal basis with others. There would be no use in identifying the rights of persons with intellectual disabilities in the UNCRPD unless they have effective tools to enforce these rights. So as to ensure that Article 12 and the other rights under the convention do not remain mere empty declarations, Article 13 **anchors the right of the concerned persons to effective law enforcement, and the right to access to justice.**

Article 13 also has strong ties to some of the **general provisions** of the UNCRPD, particularly:

- States Parties have a general obligation to create the conditions for the of **actual implementation of rights** under the UNCRPD (Article 4, (1)(a)). A fundamental condition of implementation of rights is the access to justice.
- The principle of **reasonable accommodation** influences the whole convention (Article 2, (3)(b)). It means that society has to take all necessary steps to enable people with disabilities to exercise their rights effectively, as far as it does not put a disproportionate burden on society.

It is not enough to declare that the system of justice should be accessible for everyone, because **there are several characteristics of legal systems that** hinder access to justice by persons with intellectual disabilities. Article 13 identifies these obstacles and calls for them to be eliminated.

### 4. MAKING JUSTICE ACCESSIBLE

Article 13 of the UNCRPD gives some important **examples** of how access to justice can be improved: taking account of the persons age during judicial proceedings, improving participation both as a litigant and as a witness, disability awareness training for the judiciary and administrative staff

Some **typical obstacles are highlighted:**

#### **Tips for the trainers**

*Objective of the exercise: to make the training participants understand what practical and other barriers hinder the access to justice and the enforcement of rights for intellectually disabled people and what reasons could lead to someone being unable to seek legal remedy in the case of violation of their rights. The aim is to identify the possible obstacles, as later sections of the curriculum will address the different actions in order to avoid certain impediments, so the practice aims at facilitating the registration of later parts of the curriculum.*

*Brainstorming exercise: list the possible obstacles to justice for persons with intellectual disabilities. List points identified in two columns on a flipchart, under headings: 'legal' and*

*'practical' obstacles.*

- **Legal obstacles:** either as a litigant or as a witness
- **Practical obstacles:** physical and/or communication obstacles in appearing before the court

Below are the steps to securing justice in the face of these types of obstacles.

## 5. PROMOTING ACCESS THROUGH PROCEDURAL RIGHTS

### a. Promotion of proceeding as a party

Laws on civil procedure normally deny the right of persons with intellectual disabilities with a restricted legal capacity status to proceed independently as a party to legal proceedings. Processes for substituted decision-making<sup>7</sup> must be revised in the light of the UNCRPD, which is likely to impact on any related rules for people with an intellectual disability proceeding as a party to a legal case. In those countries where the ability to litigate is not bound to a specific legal capacity status, but can be examined case by case by the court or the authorities, the professional supporters of persons with intellectual disabilities should promote the individual proceeding of concerned people, providing the necessary and due personal assistance. In many instances, persons with intellectual disabilities will require access to justice to challenge denials or restrictions of their legal capacity.

If the **supporters** of persons with intellectual disabilities **have some procedural rights** in these cases (e. g. to appearance, immediate consultation make statements, help with communication etc.), they have to use this opportunity to assist the supported person. The supporter should give full assistance to the supported person to understand the proceedings, the language being used, and be able to make decisions reflecting the will and preferences of the person they are supporting.

#### **Tips for the trainers**

*Objective of the exercise: to make the participants understand the importance of the supporter in helping people with intellectual disabilities to act independently in any litigation they are involved in through appropriate supporting.*

*Role play for individuals (individual processing of the exercise and open discussion of the results).*

*Under the civil procedure law in country Steve L., the appointed supporter a party is entitled to be present in the judicial hearings and provide any kind of assistance required to guarantee for him /her the equal opportunities during the process. Steve L. stands as a supporter by the plaintiff with mild intellectual disability and severe loss of hearing. The subject matter of the litigation: claiming back a loan (50 euros) from the plaintiff's brother (the defendant) which has not been paid back in due time. What kind of assistance can Steve L. provide to the plaintiff?*

### b. Promotion of proceeding as a witness

<sup>7</sup> Such as: rules on guardianship, conservatorship, trusteeship, curatorship etc., without regard to the actual term in the given country. On the definition of substituted decision-making see: raining module V (sec. V.2.).



Both criminal and civil justice proceedings regulate, and often restrict, the freedom of persons with intellectual disabilities to give **testimony**. This can be very discriminatory to people with intellectual disabilities, as they may be prevented from giving evidence as victims, witnesses or parties to a case. The abolition of substituted decision-making may help to ensure that people with intellectual disabilities are recognised as being competent to testify in court. However, amendments to the laws of evidence and procedure may also be required to ensure effective access to justice.

In countries where these restrictions, tied to legal capacity status, apply, **professional supporters of persons with intellectual disabilities should do all that they can to ensure that the person with an intellectual disability understands their responsibilities as a witness, can give their own evidence and is legally represented**. If court procedural rules allow, supporters should be **present at the hearing**, and should ensure that the supported person is also present.

The **warning** of the obligations of a witness (e. g. telling the truth) and the consequences of a false testimony has to be formulated in a manner that is accessible to witnesses with intellectual disabilities.

## **6. MAKING THE FACILITIES OF THE JUSTICE SYSTEM ACCESSIBLE**

### **a. Accessibility of court buildings**

Persons with severe and/or multiple disabilities may have difficulty in entering court buildings that are often old and not designed with the needs of people with disabilities in mind. Supporters should do everything possible to assist with physical access and seek to use any regulations that allow for a witness statement to be given at a different location.

In all proceedings effecting the person, especially proceedings concerning the exercise of legal capacity, persons with intellectual disabilities should be supported to be present and to participate in the proceeding.

### **b. Accessible communication and information**

Judicial authorities seek to respect the law by communicating in a very formal way, often using jargon and describing procedures in a way that can be very difficult to understand. Procedures can also be very formal and intimidating. Judicial authorities should be encouraged to create easy read information materials and to make their procedures more user friendly. Supporters should do all that they can to help the person with intellectual disabilities take part in the proceedings.

Professional advocates or supporters of persons with disabilities could seek to influence judicial practice through lobbying activity or actual cooperation either on a voluntary or contracted basis.

### **c. Awareness training for judicial staff**

To ensure that people with intellectual disability have good access to justice, authorities should be encouraged and lobbied to introduce disability awareness training for their staff and the judiciary.

## 7. VIDEOS

### Dee's place

Living independently is something most teenagers look forward to. So it wasn't a surprise when at 18, Dee Holmes told her mum and dad that she wanted to live in her own place, like her brothers. But for people like Dee, who have intellectual disabilities, finding the enough support to live with independence is difficult. Guidance is out there, but you need to know where to turn.

<https://www.youtube.com/watch?v=ezdSrX7MNBO&list=PLGzj8qPIUSqghf-6QNFjqrfx4YIJ5ebf&index=7>

For more films check out the Twenty Years:

<http://www.humanrights.gov.au/twentystories/videos.html>

or video is by Communication Disabilities Access Canada:

<https://www.youtube.com/watch?v=WqxBJGuwtPk>

## 8. BIBLIOGRAPHY AND RESOURCES

Ortoleva, S, Inaccessible Justice: Human Rights, Persons with Disabilities and the Legal System, 17 ILSA Journal of International & Comparative Law 281 (2010-2011), 282-298

Morrissey, F., The United Nations Convention on the Rights of Persons with Disabilities: A New Approach to Decision-Making in Mental Health Law, European Journal of Health Law, vol. 19, 2012, 423-440

Rhode, D., Access to Justice: Connecting Principles to Practice – 2004 Symposium Articles, 17 Georgetown Journal Legal Ethics 369 (2003-2004), 372-387

### ***Tips for trainers***

*Please include possible resources at national level*

## V. Promising examples and practices

### OBJECTIVES OF THE MODULE

- To provide participants with examples of the most promising practices of legal capacity and access to justice internationally.
- To offer participants an opportunity to review some of the Promising Practices identified by the AJUPID project and give an overview to the larger group.  
Key message
- This module offers participants an opportunity to acquaint themselves with some examples of promising practices internationally, this knowledge will prompt trainers to reflect on how some of these practices could be implemented in national contexts.

### LESSON PLAN FOR MODULE

Recommended length: 1 Hour 20 Mins

Item	Tool	Timeframe
Module Overview	Presentation	5 min.
Definition of Promising Practices	Presentation & Video	10 min.
Overview of 2 Promising Practices	Presentation & Video	20 min.
Practical work in pairs	(focus on AJUPID promising practice guide)	15 min.
Feedback to larger training group.	Exchange	30 min.

### Definition of Promising Practices:

A promising practice incorporates the philosophy and values shared by the partners of the AJUPID project; these are based on the UNCRPD and our common interest to support people with disabilities in enjoying their legal capacity and gaining access to justice.

#### ***Tips for the trainers***

*Please refer to the "Guide of Promising Practices" which includes descriptions of 13 European and International practices supporting legal capacity and access to justice. Please reflect on how you might adapt the practice in your own context.*

## **1. INTERNATIONAL EXAMPLES**

### **a. Representation Agreements, British Columbia, Canada**

The Province of British Columbia, Canada is one of the leading jurisdictions in incorporating supported decision-making into law, policy, and practice. An individual with disabilities can enter a "representation agreement" with a support network. The agreement is a sign to others, including doctors, financial institutions, and service providers, that the individual has given the network the authority to assist him/her in making decisions, and to represent him/her in certain matters.

One of the main innovations in the legislation is that persons with more significant disabilities can enter into representation agreements with a support network simply by demonstrating "trust" in the designated supporters. A person does not need to prove legal competency under the usual criteria, such as having a demonstrated capacity to understand relevant information, appreciate consequences, act voluntarily, and communicate a decision independently, in order to enter this agreement.

A number of individuals and support networks have entered representation agreements as an alternative to guardianship or other forms of substitute decision-making. A community-based Representation Agreement Resource Centre assists in developing and sustaining support networks by providing information, publications, workshops, and advice. The Centre also oversees a registry in which a network can post an agreement for other parties to view if required before entering a contract with the individual. For more information see <http://www.nidus.ca>.

Internationally, British Columbia's Representation Agreement Act [2] is recognized as pioneering legislation, being one of the first legal regimes for supported decision-making. The Act was introduced in 2000, Other Canadian jurisdictions have since enacted legislation that recognizes supported or assisted decision-making to some degree, using different language and legal frameworks, generally as part of adult guardianship and adult protection legislation.

### **b. The Jenny Hatch Justice Project (JHJP), Washington DC U.S.A.**

The JHJP is a resource and outreach Centre dedicated to advancing people with disabilities' right to make their own choices and determine their own path and direction in life.

Like many people with disabilities, Jenny faced a guardianship petition challenging her right to make decisions, choices she had always made for herself like where to live, what to do and who to see.

After a year of litigation and six days of trial, Jenny won the right to make her own decisions and now lives and works where she wants, has the friends she chooses and encourages others to do the same. The "Justice for Jenny" case is the first to Order the use of Supported Decision-Making instead of plenary guardianship for a person with a disability and received national and international attention for highlighting "an individual's right to choose how to live and the government's progress in providing the help needed to integrate even those with the most profound needs into the community.

Jenny's strength has inspired many others to seek their own justice.

The JHJP project coordinates and produces resources to address the legal, policy, research, and practical issues related to decision-making and support for people with disabilities and their families.

**Tips for the trainers**

*Reflective work in pairs*

*Review of AJUJID Promising Practices.*

*Trainer selects 2 practices and informs pairs.*

*Feedback to larger group on*

*Why a particular practice is deemed promising?*

*How it might be duplicated in a National context?*

**c. Independent Third Person (ITP) Programme, Victoria, Australia**

The Independent Third Person (ITP) programme in the State of Victoria, Australia is a service provided to people with a cognitive disability or mental illness during interviews with police. ITPs are volunteers trained by and registered with the Office of the Public Advocate in Victoria and provide communication support to individuals, as well as help them understand their rights. The service is available to victims of crime as well as offenders.

The ITPs for support the individual to communicate with the police, providing guidance to the police on how to interact with the person, and advising the police if the person with a disability does not understand their rights at any stage of the process. Responsibility for contacting an ITP lies with the Victoria Police, but an individual with a disability or someone close to them can also request access to an ITP if they wish. ITPs do not replace the role of legal representation, and do not provide legal advice to the person with a disability but are merely present as a formal support for the person to increase the accessibility of the police system.

In a report entitled 'Breaking the Cycle', the Office of the Public Advocate interviewed people with disabilities who had used an ITP in their contact with police, family members, ITPs and professionals about the ways in which this programme could tackle the links between poverty, social isolation and crime, for people with cognitive disabilities.<sup>8</sup> Overall, the experiences of those interviewed were positive, although there were some concerns regarding long-term support for individuals who used the programme, especially those who used the programme more than once, given the short-term nature of the assistance the ITP provides.<sup>9</sup> As a result of this research, the Office of the Public Advocate has committed to implement a two-year pilot advocacy and referral scheme, to link those who use the ITP service to other supports as part of an early intervention strategy in the criminal justice system.<sup>10</sup> This commitment is a positive example of the types of support that can be provided by law enforcement, in partnership with other public bodies to ensure that people with disabilities are reasonably accommodated, and adequately supported through the criminal justice process.

<sup>8</sup> Office of the Public Advocate, *Breaking the Cycle: Using advocacy-based referrals to assist people with disabilities in the criminal justice system* (Melbourne: 2012).

<sup>9</sup> Office of the Public Advocate, *Breaking the Cycle: Using advocacy-based referrals to assist people with disabilities in the criminal justice system* (Melbourne: 2012), 10.

<sup>10</sup> Office of the Public Advocate, *Breaking the Cycle: Using advocacy-based referrals to assist people with disabilities in the criminal justice system* (Melbourne: 2012), 7.

## 2. BIBLIOGRAPHY AND RESOURCES

**Compulsory Literature: AJuPID 2015 "Guide of promising practices on legal capacity and access to justice - Reflections for the implementation of the articles 12 and 13 of the UN Convention on the Rights of Persons with Disabilities",** [www.ajupid.eu](http://www.ajupid.eu)

E.U. Person Community Partnerships to ensure reform of supports in other Nations, [www.eu.person.com](http://www.eu.person.com)

Bach & Kerzner 2010: A New Paradigm for Protecting Autonomy and the Right to Legal Capacity, <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf>

Inclusion Europe on Legal Capacity, <http://inclusion-international.org/category/priorities/legal-capacity/>

Platform on Supported Decision-Making for People with Disabilities (choices), [www.right-to-decide.eu/](http://www.right-to-decide.eu/)

Supported Decision Making Dialogue Guide, <http://inclusion-international.org/supported-decision-making-dialogue-guide/>

The Law Commission of Ontario 2012: Understanding the lived experience of supported decision making in Canada Study paper.

## VI. Communication with people with intellectual disabilities

### OBJECTIVES OF THE MODULE

- Comprehend communication skills and needs of persons with intellectual disabilities
- Provide participants with tools to adapt communication to the needs of persons with disabilities

Effective communication is a prerequisite in supporting persons with disabilities to enjoy their legal capacity and access to justice. One of the main obstacles in obtaining rights is a lack of appropriate communication that will help understanding the will and preferences of a person with intellectual disabilities. In addition, access to justice can be obtained more easily if communication tools are used to support persons with disabilities to testify in court, for example.

Supporters can play a crucial role in helping persons with disabilities to express their wishes and to communicate with third parties.

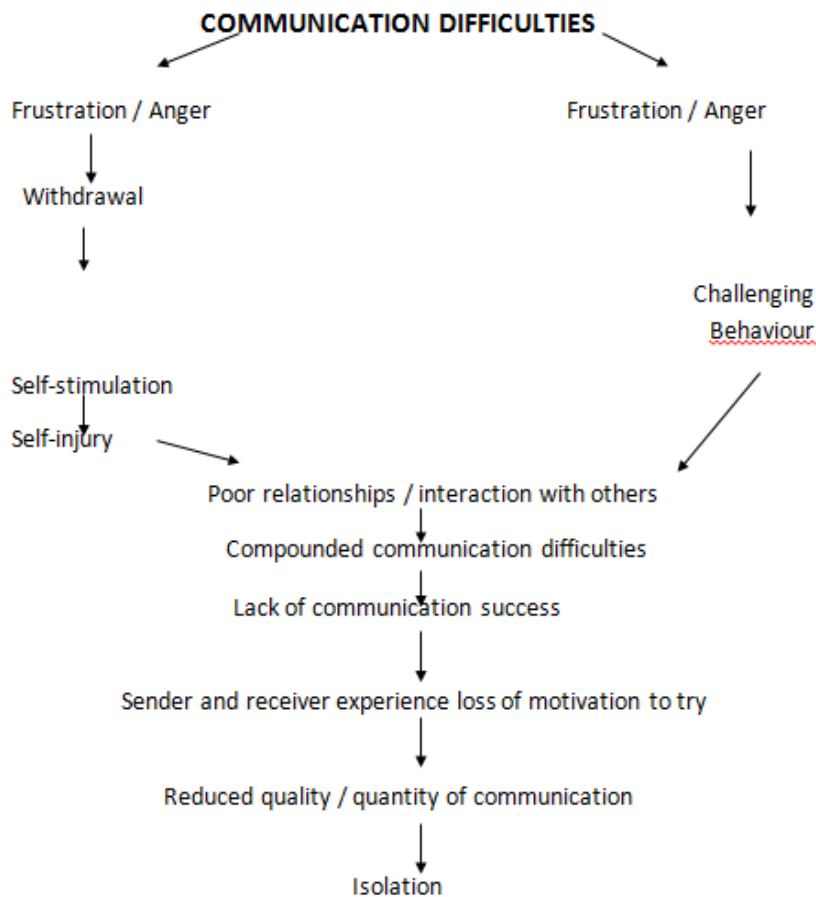
### LESSON PLAN OF THE MODULE

#### 3. LESSON PLAN OF THE MODULE

Recommended length: 2 hours

Item	Tool	Timeframe
Introduction	Role Game	10 min.
Adapting communication to the skills and needs of persons with intellectual disabilities	Presentation	10 min.
	Discussion	10 min.
Communication and its role in the developing new skills	Presentation	15 min.
	Brainstorming	10 min.
making choices	Presentation	15 min.
	Discussion	15 min.
The communication checklist	Presentation	10 min.
Discussing problems	Exchange	10 min.
Conclusion	Presentation	15 min.
	Discussion	

## 1. ADAPTING COMMUNICATION TO THE SKILLS AND NEEDS OF PERSONS WITH INTELLECTUAL DISABILITIES



It is an important first step to understand each person's unique way of getting their message across. This can vary from person to person, and can depend on the person's level of spoken language, their eye contact, and their body language. Each individual is recognized as having their own particular way of communicating. Without an understanding of this we will struggle to achieve a person centred approach, hear about people's hopes and needs, and achieve a better life for each person.

Communication has different forms, only one of which is verbal communication. People communicate in different ways and we should allow people to express themselves in the way they feel most comfortable. Only 30% of communication is verbal and only 15% of a decision made after a conversation is actually based on that conversation, the rest on the basis of non-verbal communication.

If communication is not effective we can expect difficulties and unexpected results.

### a. Communication tools to change the attitude toward persons with intellectual disabilities

People with intellectual disabilities are **individuals**. You need to try to look at things from **their** perspective. Remember, it is their agenda that is most important, not yours.

People with intellectual disabilities have feelings, and are sensitive to situations, experiences and the attitudes of others. If they never experience successful communication, and fulfilling relationships that make them feel good about themselves, they may give up. They may be happy some days, and want to chat, or down some days, and prefer to be quiet - just like everyone else!

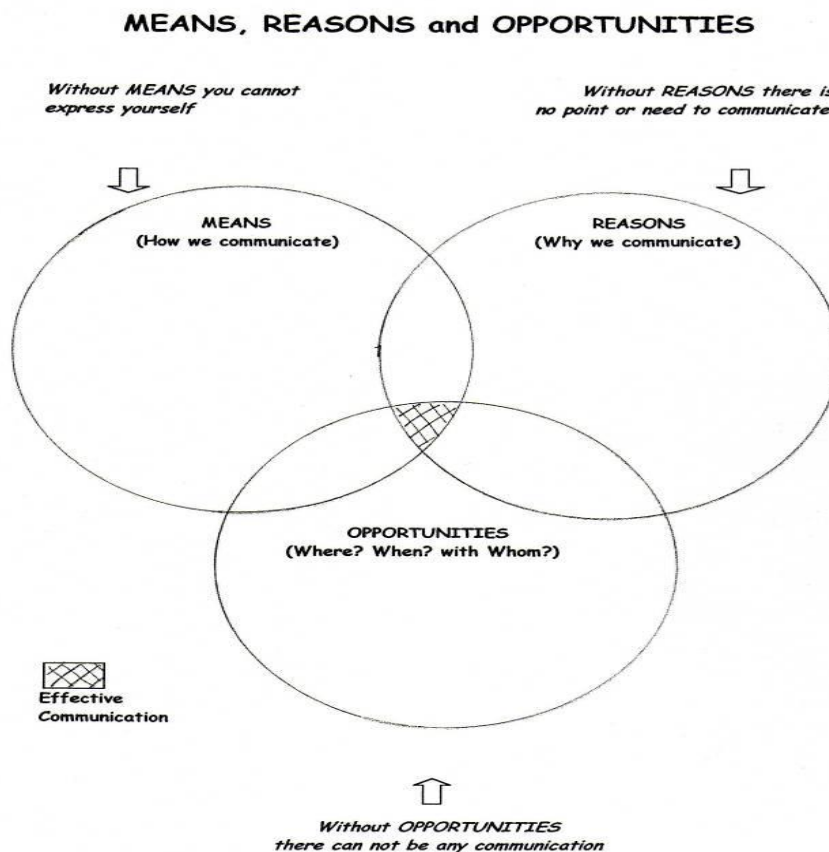


## What is most important in communicating effectively with people with intellectual disabilities?

- Put the person with intellectual disabilities at the **centre**
- Do things **with** the person, not **to** them or **for** them
- Understand the person's abilities, needs and interests
- Seek to find out what is important to the person from their perspective
- Seek to know what support the person needs to get the best out of life
- Seek to help the person make choices and decisions
- Effective communication results in **changes** which improve the quality of life of the person with intellectual disabilities
- It is an ongoing **process**, not a one-off meeting.

## How can we communicate more effectively?

- Sentence length
- Vocabulary
- Amount of language
- Rate of communication
- Intonation
- Use of signs and symbols
- Facial expression
- Gesture
- Attention



### **Tips for the trainers**

**EXERCISE:** Answer certain questions or ask questions without using words

*Aim: importance of getting the message across in creative ways*

## **2. COMMUNICATION AND ITS ROLE IN THE DEVELOPING NEW SKILLS**

### **How do we know what someone wants? How do we know what someone needs?**

How do we know what interests someone? We find out through **communication** with that person. If you are communicating with someone, you are their **interacting partner**.

#### **a. The person at the centre**

People with intellectual disabilities can learn new skills and adapt their behaviour to different situations, especially if they are provided with the right opportunities and challenges and the right support. Often, though, the greatest change will come from the **interactive partners**, from changes to the **environment**, and by making **information** more accessible. Even small changes here may really help the person to develop their skills and understanding.

**Interactive partners** may need to change their style of communication. **The environment** may need changing to make communication effective. **Information** may need to be adapted and presented in different ways.

Good communication depends on:


- How well you can hear
- How well you can see;
- How comfortable you are feeling;
- How alert and attentive you are;
- How well you can understand what is happening;
- How well you can express yourself to someone else;
- How interested and motivated you are to communicate.

#### **People with intellectual disabilities often:**

- **Have unidentified health needs that affect communication**
  - Hearing or visual impairments; epilepsy; pain; physical difficulties that make communication difficult; medication that adversely affects attention and concentration.
- **Do not understand everything that is said to them**
  - They may appear to understand, but actually be responding to your tone of voice, or familiar cues in the situation. They may misunderstand, forget or not catch some of what you say. They may often say "yes" in answering questions, even if they do not fully understand - partly because they do not want to make difficulties. They may not be able to contradict you if you have misunderstood what **they** mean or want. They may be bilingual, and have greater skills in one language than another.
- **Use many different ways of communicating**
  - Facial expressions, eye gaze, "body language", gestures, signs, communication books and charts with pictures or symbols, objects, electronic aids
- **Need time to understand and respond to you.**

- Some people take longer to process what you are saying. Others may find physical movement or speech requires effort, so that it will take longer to respond.
- **Interactive partners often overestimate the understanding of people with intellectual disabilities, and make their language too complicated.**
  - This puts too many demands on the person, who may withdraw, show challenging behaviour, or fail to do what is asked. **Challenging behaviour is often caused by a person's failure to understand what is going on, or inappropriate demands from others.**
- **Interactive partners often do not use all the ways of communicating that are appropriate to the person.**
  - This means that a person's own communication system is not valued, and may deter them from using all their skills effectively.

**THINKING ABOUT PEOPLE**



**What you need to do**

- Make sure the person can hear, see and is comfortable
- Check when the last hearing or vision test happened; get an up to date assessment
- Make sure hearing aids or glasses are used if necessary, and that they work properly!
- Make sure you talk clearly and allow the person to read your lips if necessary
- Use sign /gesture and pictures to back up your speech
- Make sure you present information clearly for people to see
- Make sure people are positioned for good communication - seating is key
- Make sure the environment is quiet and there are not too many distractions
- Check out general health and comfort- pain, physical difficulties, effects of medication.

**What you need to do:**

- Look for the evidence to support your interpretation of what the person means.
- Be a good observer. Keep a record of someone's responses over time to different situations. Look for patterns of behaviour.
- Talk to others who know the person. Put all your ideas together.
- If you are not sure what someone means, make a guess and stick with it. Keep a record of how the person responds to your interpretation of their behaviour. Review the situation later on with other people – if your interpretation seems wrong, try another one!
- Talk to speech and language therapists and psychologists who may be able to help with observations



I use many different forms of communication - speech is often difficult. Don't forget my communication book!

If I sometimes behave in ways that challenge you, it may be because I am not understanding what is happening.

**What you need to do**

- Make sure you keep your language simple and clear.
- Gain a person's attention before starting to talk.
- Show that you respect a person's way of communicating by using it to them.
- Make sure communication books/aids are available to the person when they need them - not stuck in a cupboard!
- Be a good observer, and respond to all communicative signals.
- Make sure the person can see your hands and face if you are signing and talking.
- Give enough time for the person to listen to you and respond.
- Check that you have understood - by talking to others, helping the person to tell you when you have got it wrong. Don't pretend you can understand if you really can't!

- Speech and language therapists can help you to decide the best way of communicating with people with learning difficulties - have you got contact details?
- You can talk to families, friends and advocates to find out more about someone's communication.

## b. Making information accessible

If people are to be able to make choices about their lives, they need **information** about the options available to them.

There are many ways of making information **accessible** to people with intellectual disabilities. These include the different ways of communicating that we have mentioned above, but also ways of presenting information so that people can become more engaged in the process.

### You need to consider:

- What method or combination of methods will be most useful to the person
- How to give the person ownership and control over information about themselves.
- Allowing enough time to produce information and resources
- Linking with other services to make sure that everyone is consistent in what they are doing
- How to store and catalogue resources, so that they do not get mislaid
- Your own training needs – do you need to go on a signing or ICT course?

**Example:** Andreas has profound learning difficulties and communicates only through sounds and movements. At lunchtimes he is helped to eat by staff, whose rota changes on different days. In discussion with the speech and language therapist, it emerged that half the staff thought that when Andreas vocalised towards the end of the meal, he wanted more food, while the rest of the staff thought he was signalling that he had had enough. Because they had different beliefs about the meaning of the communication, Andreas was getting very inconsistent responses, which did not help to develop his skills.

**INTERACTIVE PARTNERS: THINKING ABOUT MEANINGS**

I think he's had enough.

muh-muh-muh

I think he wants some more

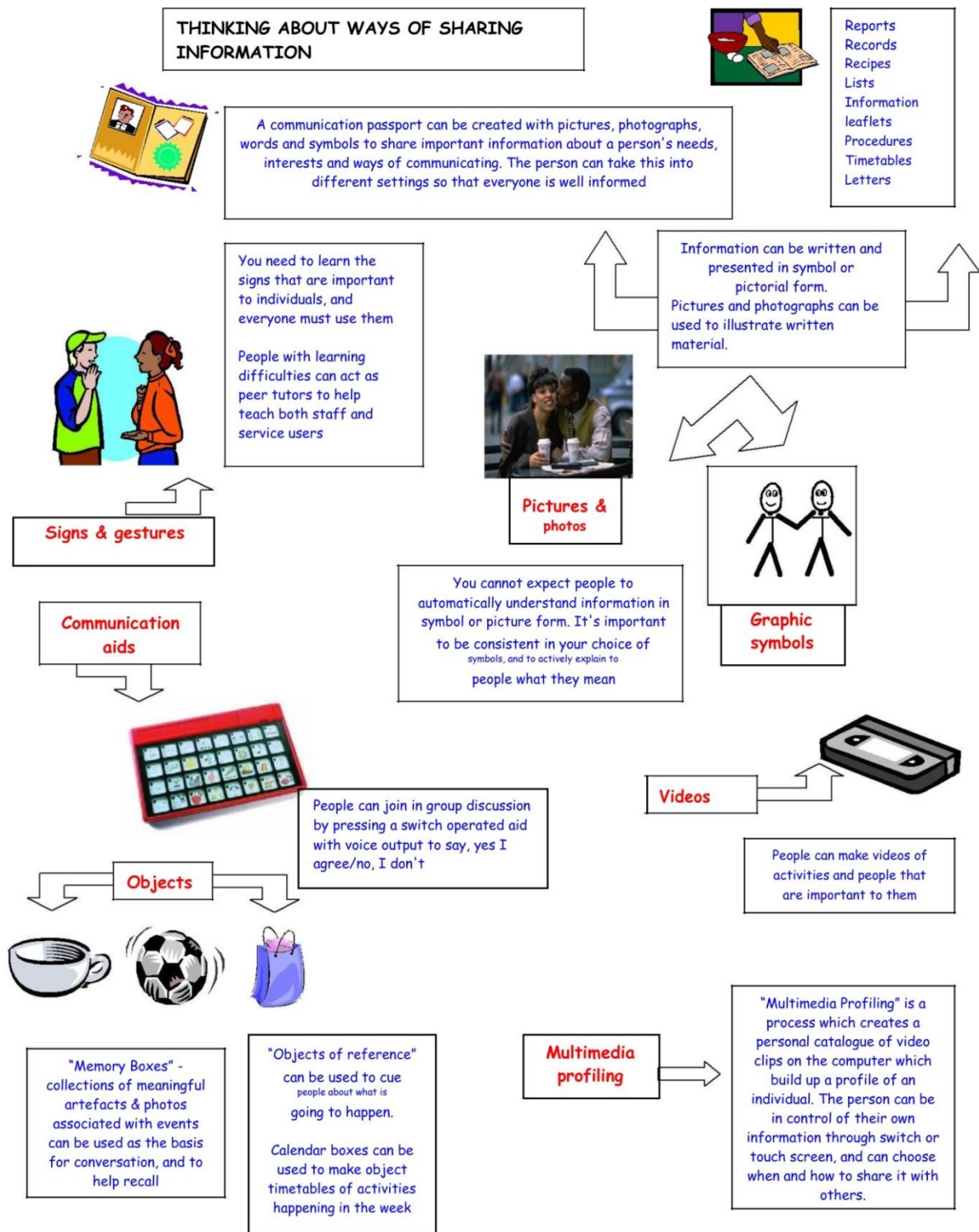
Let's discuss it. I'll watch and make notes about his behaviour in other situations when we know he's had enough, or when he wants something

And I'll go and talk to his mum at home and see what she thinks

He seems to look like this and make this sound when he wants things - like in the sensory room. When he's had enough, he pushes things away.

His mum says she usually gives him another mouthful when he makes that s

## Sharing information



- A **communication passport** can be created **with pictures, photographs, pictograms, words and symbols** to share important information about a person's needs, interests and ways of communicating. The person can take this into different settings so that everyone is well informed.

We recommend the use of supportive communication tools. Examples include **Ela Photoseries/Every Day Life Activities/, Makaton, Loeb System** etc.

- You need to learn the **signs** that are important to individuals, and everyone must use them
- **"Memory Boxes"** - collections of mementos & photos associated with events that are meaningful to the person and can be used as the basis for conversation, and to help recall.
- "Multimedia Profiling" is a process which creates a personal catalogue of video clips on a computer which build up a profile of an individual. The person can be in control of their own information through switch or touch screen, and can choose when and how to share it with others.  
<http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-thinking/person-centred-thinking-tools/communication-chart.aspx>

## The physical environment

Here we consider the physical environment surrounding a person with an intellectual disability. Changing this can often facilitate both understanding and spontaneous expression. Therefore we need to consider:

- Noise levels
- Seating
- Lighting
- Heating level
- Group Dynamics
- Atmosphere

## There are lots of ways in which physical space can affect communication

- Noise makes it hard to hear, and makes us tense and jumpy
- Furniture arranged in a formal way, in lines or around a table, can make us feel inhibited.
- Big spaces make it hard to hear and see people
- People coming in and out make us feel our communication is not private
- Uncomfortable chairs mean we don't feel at ease
- Bare rooms mean there are fewer topics for conversation
- Unpainted dirty rooms make us feel devalued and worthless
- Think about **changing the physical environment:**
- Quiet spaces that are not interrupted by others make us feel relaxed
- Comfortable furniture in small groups helps us to see and hear others, and give attention to what is happening
- Flowers, pictures, personal possessions and nice things to look at and touch give us things to talk about.
- Making the room familiar by including things we can relate to, helps us feel at home
- The environment can be labelled and signposted to help people become more independent – putting pictures or symbols on cupboards to show what's inside; using tactile and visual lines to help people find their way.
- Well maintained spaces make us feel we are worth talking to.

### 3. MAKING CHOICES

The ability to make good choices depends on experience, opportunities and the chance to learn from our mistakes.

#### Small steps

Big decisions are the outcome of small decisions. Seeing things from the perspective of the person at the centre means being aware of the importance of small changes. Choosing what to wear or where to sit, or what music to listen to may not seem very significant from our point of view - but these small changes can make someone feel effective and in control of a manageable part of their lives.

#### Choice making cycle

- We need a range of experiences that offer us contrasts
- We need to reflect on those experiences by thinking and talking about them
- We need opportunities to make choices of different experiences
- We need particular means to make a choice and communicate it to others
- The best time to look at choice making is when people are in the actual situation and need to make real choices, rather than talking about choices in the abstract.

Learning to make choices also involves learning **how** to make choices. This means that we need to make the procedures of planning clear and accessible. Having predictable routines that are used consistently will help the person to participate actively. The more consistent experiences we have of making effective choices, the better we get at it.

#### You need to consider:

- What choices will matter to the person
- How the person communicates a choice
- Starting with small choices before expecting big choices
- Making choices in the actual situation, rather than outside it
- Providing an appropriate range of experiences, so that a person has some sense that it is possible to do something in a different way - and therefore make a choice
- How to make sure that a choice results in a meaningful outcome
- How to help a person understand that sometimes they cannot have what they want
- The resource implications of choice making: for example, increased budgets for food and leisure
- How to give a person experience of the procedures and conventions involved in making choices and decisions

#### Making decisions involves lots of **skills and experience**:

- You need to present choices in ways that the person can manage.
- You need to help the person have a rich life with lots going on.
- You need to provide good choice making opportunities in everyday situations.
- You need to help the person develop the skills to look at alternatives and pick one of them – even simple things like what clothes to wear.
- You need to be ready to listen to the person and act on what he wants if it is possible.
- You need to be realistic about the resource implications.
- You need to find and use good ways of helping the person communicate.



- You need to collect evidence of what the person likes and dislikes and talk to others, being careful not to assume that you know best. You need to work with the person to review them.
- You need to provide the person with choices that have consequences-if it never matters what the person chooses they will never be motivated to make a choice.
- You need to develop some strategies for explaining why things cannot happen.

## Arranging meetings with others

### *What you need to do:*

Help the person with disabilities to choose:

- Where to have the meeting → somewhere comfortable and familiar
- Who will come
- Ways of presenting and sharing information
- Ways of recording what happens
- Make the social situation comfortable
- Always introduce people
- Don't use jargon
- Keep the person at the centre

### **Molly's example**

Molly is nine years old. One day she said to her parents that she liked a person she had met at a party. When her parents asked why she liked that person, she replied:

He looked at me when he was talking to me

He made me laugh

He talked to me about things that were interesting

He used my name when he spoke

Sometimes he just smiled and listened

*Molly's approach is very basic but they work!*

## Communication processes

- Communication is designed to be a process that evolves over time, and times change.
- The choices and decisions we make about our lives are outcomes of a gradual development of self-awareness - involving small steps and changes.
- Communication involves a cycle of opportunity, experience, reflection and decision-making.

The process of communication takes place over time. Over time, health changes, likes and dislikes change, and skills and abilities change as we lose some and gain others.

### **Example:**

Hearing may have been fine a year ago - but colds and ear infections since then may mean that now there is a hearing loss.

Vision may have been fine a year ago - but ageing may mean that the person now needs glasses

A particular medication may have suited the person a year ago - but now they have developed resistance to it.

A year ago, the person may have really liked a particular food or music - but now they are bored of it and would like to try something new.

A year ago, the person had a close friendship with another individual - but now they have drifted apart.

In the process of communicating we must be careful not to make assumptions:-

- There should be a balance in someone's life between familiar and new experiences, so that change is possible.
- A profile should be an ongoing process, which is responsive to changes in a person's circumstances.
- Hold regular reviews which allow for new perspectives and ideas

**Examples:**

Guidelines for communicating with a person with an intellectual disability and impaired hearing, blind

- Approach the person within their field of vision
- Gain the persons attention before starting the conversation
- Face the person directly, give clues through facial expression
- Speak normally, naturally and clearly
- Don't turn away during talking
- Eliminate background noise whenever possible
- Rephrase rather than repeat
- A person's ability to hear may vary
- Smell
- Object of reference
- Jewellery
- Sign Draught
- Vibration
- Sound/sight

**4. THE COMMUNICATION CHECKLIST**

1. We should always keep in mind and use the communication 'checklist'
2. What is special about this individual?
3. Does the person need a: hearing test/vision test/health check. Date of last test:
4. What aspects of health and physical status affect communication?
5. What do you think the person can understand?
6. Are there any clues to suggest comprehension problems?
7. How does the person express themselves best?
8. What do you need to do to support communication?
9. What helps you to understand the person?
10. Are there different views about the person's interests, needs and communication, which might lead to disagreements?
11. What methods should you use to make information accessible to the person? eg. signs and gestures; pictures and photos; symbols; written words; objects; video; communication aids; multimedia
12. Do you need to make changes to the environment to support communication? eg. smaller spaces, reducing noise, changing the furniture, access to personal space.

## 5. BIBLIOGRAPHY AND RESOURCES

Communication Matters - representing people who use augmentative and alternative communication, professionals and manufacturers. <http://www.communicationmatters.org.uk>

Acting Up - works with people marginalised by severe communication difficulties and institutionalised practice. They have developed multimedia profiling to support inclusion. <http://www.acting-up.org.uk>

Somerset Inclusion Project - developed a total communication approach using signs, symbols, picture and communication aids to support participation in the community

Foundation for People with Learning Disabilities: Communication for Person-Centred Planning  
[http://www.learningdisabilities.org.uk/content/assets/pdf/publications/communication\\_p\\_c\\_planning.pdf](http://www.learningdisabilities.org.uk/content/assets/pdf/publications/communication_p_c_planning.pdf)

CHANGE picture bank - set of pictures to help make information easier to understand. [www.changepeople.co.uk](http://www.changepeople.co.uk)

Makaton Vocabulary Development Project - training and resources in the use of signs and symbols with people with severe communication difficulties, [www.makaton.org](http://www.makaton.org)

Talking Mats - can be used to help people who can understand pictures and symbols to talk about issues that are important to them, [www.aacscotland.com](http://www.aacscotland.com)

Everyday Life Activities (ELA) web site: [www.ela-photoseries.com](http://www.ela-photoseries.com)

## VII. Role of families and links with supporters of legal capacity

### OBJECTIVES OF THE MODULE

- to provide participants with an understanding of the role of the family in supporting relatives to exercise their rights under the UNCRPD;
- to provide participants with an understanding of the links between family, professionals, services and the broader community;
- to define the role of families in the development of decision-making skills.

### KEY MESSAGES OF THE MODULE

Family members are the first natural supporters of persons with disabilities.

Professionals, family members and other supporters should work together in order to support the person with disability in the best possible way.

An empowered family member knows about the rights of their relative with disabilities. The family member respects the rights of their relatives, allowing them the dignity to make decisions on their own, even if they involve risks.

Family members have a crucial role to play, in case the rights of the person with disability have been violated.

### LESSON PLAN OF THE MODULE

Recommended length: 2 hours

Item	Tool	Timeframe
Introduction	Card Game – Easy*	15 min.
Role of families	Brainstorming*	10 min.
Box: Dignity of risk	Presentation	15 min.
Supporting your relative	Brainstorming*	10 min.
The empowered family members	Presentation	15 min.
The tripartite partnership	Human Knot* & Diagrams	20 min.
Dealing with conflict	Exchange*	10 min.
Conclusion	Card Game* - Difficult	20 min.

\* Co-training by persons with intellectual disabilities is encouraged.

#### **General tip for trainers about this module:**

*The training is about ADULTS and not children (in this module about family, the conversation could easily go in the wrong direction)*

## 1. FAMILY: THE FIRST NATURAL SUPPORTER

### **Tips for trainers / Card Game**

*Use the card game (easy) to discuss a few of the scenarios at the beginning of the module.*

*Objective : Trainees understand the challenges around decision-making for persons with disabilities and their supporters.*

### a. **The responsibilities of the family as informal carers and supporters**

#### **Tips for trainers / Brainstorming**

*Organize a brainstorming: What are the current situations of families in supporting the legal capacity or access to justice of their relatives? (Use a flipchart or post-its).*

*Objective: To help trainees understand the paradoxical role family members have in supporting legal capacity and access to justice & to help the trainees to realise that there is no "right" or "wrong" answer in terms of dignity of risk.*

**The UNCRPD acknowledges the important and crucial role of families in promoting the human rights and inclusion of persons with disabilities.** Often, whether through natural commitment or due to their legal responsibilities, members of the family play a major role in supporting the person with an intellectual disability: they often live together, are frequently the persons **natural first point of contact** concerning many, if not most, aspects of their lives.

**In many situations, it is the family's voice and concerns that frame decisions made around a person.** Consequently, family members find themselves in a paradoxical role:

- On the one hand, **concerned with the safety** of their sons and daughters, particularly in a society that is not fully receptive and inclusive.
- On the other hand, **they should support their relative** to have a voice and gain increasing control over their lives, while often assuming formal decision-making roles as guardians, due to the lack of appropriate legislation and appropriate legal assistance.
- Moreover, **sometimes families may be blamed for poor decisions or mistakes that their son or daughter may have made.**

**Dignity of risk** means respecting each individual's autonomy and self-determination (or 'dignity') to make choices for him/herself. The concept is that all adults have the right to make their own choices about their health and care, even if family members or support professionals believe these choices endanger the person's health or longevity. For example, an individual may choose to continue smoking despite the known risks. He or she may also continue to live alone, or with only intermittent support, even if others do not approve or if they consider the choice unsafe.

These factors contribute to an over-reliance on families as decision-makers. In this context, substituted decision making is tempting because it provides the family with a form of protection.

It is therefore absolutely essential that family members are given tools they can use to support their relative to make their own decision.

In striking this difficult balance service providers and other professionals can help family members so that the person with a disability can live the 'dignity of risk.'

Finally, **the concrete realisation of the rights of persons with intellectual disabilities is strictly interdependent with the quality of life of their family members.**

In France, for example, around 10 million people are involved in caring and/or supporting a member of their family<sup>11</sup>, 87 % of persons with disabilities are supported by family members in one way or another<sup>12</sup>.

### **Tips for trainers**

*Please include national statistics.*

**NOTE: Family members are experts concerning communication, understanding and support of their relative with intellectual disabilities and this should to be recognised.**

## b. **The role of the family in the UNCRPD**

### **Tips for trainers / Brainstorming**

*Organize a brainstorming: How can family members ideally support relatives with disabilities in their legal capacity and access to justice? (Use a flipchart or post-its).*

*Objective: To help trainees to understand which duties and possibilities family members have in supporting their relatives in exercising their legal capacity and accessing justice.*

The UNCRPD explicitly underlines the role of families in the following articles:

#### Preamble

(x) Convinced that the *family* is the natural and fundamental group unit of society and is entitled to protection by society and the State, and **that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities...**

#### Article 8: Awareness-raising

To **raise awareness throughout society, including at the family level**, regarding persons with disabilities...

In the UNCRPD, there are also two articles on ***the right of persons with intellectual disabilities to create their own families.***

#### Article 22: Respect for privacy

*No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home...*

#### Article 23: Respect for home and family

*(... )to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, (...)*

<sup>11</sup> BVA, Novartis: „Les aidants familiaux en France“

<sup>12</sup> CREAI Rhône-Alpes 2009: « Les besoins et attentes des aidants familiaux de personnes handicapées vivant à domicile ».

## Article 16: Freedom from exploitation, violence and abuse

to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and **support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse.**

## Article 28: Adequate standard of living and social protection

... Recognize the right of persons with disabilities to an adequate standard of living for themselves and their families ...

### c. **The current limits of national legislation**

As the AJuPID research report demonstrates, governments are grappling with the integration of Article 12 and 13 in national legislation and their implementation.

The role of families in supporting the legal capacity of their relative is defined and framed differently, depending on the national legislation.

#### **Tips for trainers**

*Please include the role given to families by national legislation.*

### d. **The empowered family member**

Will be able to assist their relative with an intellectual disability because they:

- Are familiar with their rights;
- Know about existing support services and facilities;
- Can guide and gain the goodwill of other family members and the local community;
- Know where to find information and assistance on the relevant national/European laws and policies and judge how they protect and can assist;
- Are familiar with the concept of legal capacity and support to exercise legal capacity;
- Know the channels for seeking justice;
- Understand that their relative needs assistance and support to benefit from the same rights as others;
- Know how to build a broader network of support for family members in the broader community;
- Promote inclusion in the family and the community, and the expression of the wishes of their relative
- Understand that their relative deserves the same dignity as others, including the dignity of risk;
- Understand the concept of human rights and social justice;

#### ***The empowering model of disability:***

This approach allows for the person with a disability and his/her family to decide the course of their treatment and what services they wish to benefit from.

This, in turn, turns the professional into a service provider whose role is to offer guidance and carry out the client's decisions. In other words, this model empowers the individual to pursue his/her own goals.

- Act as a facilitator, so that the person can fully enjoy their rights;
- Help other families as a peer supporter.

**An empowered family member will understand the persons with intellectual disabilities dreams and goals and support him or her to have their own voice and to act on their own accord, keeping in mind that the person concerned will grow and learn from his or her decisions.**

***NOTE: Family members rely on behaviours and other forms of communication as an expression of will and preferences and use this to guide decision-making.***

## 2. THE FAMILY AND THE OTHER SUPPORTERS

### ***Tips for trainers / The human knot***

*Use the human knot exercise:*

<http://www.wilderdom.com/games/descriptions/HumanKnot.html>

*Objective: To demonstrate the need to cooperate and to communicate in order to find a solution.*

### a. **A tripartite partnership to build and organize**

Family decisions about inclusion are influenced by various factors:

- The level of support within the family;
- The socio-economic background;
- Participation in training and workshops;

By professional support workers and service providers.

It is important that **a common understanding of the rights of the person with an intellectual disability is shared by anyone playing a role in issues concerning the legal capacity of a person, whether they are members of the family, a friend or a professional support worker.**

**Professional support workers and service providers are crucial as facilitators** of rights for the person and can contribute to empowering family members and other supporters of legal capacity. They can:

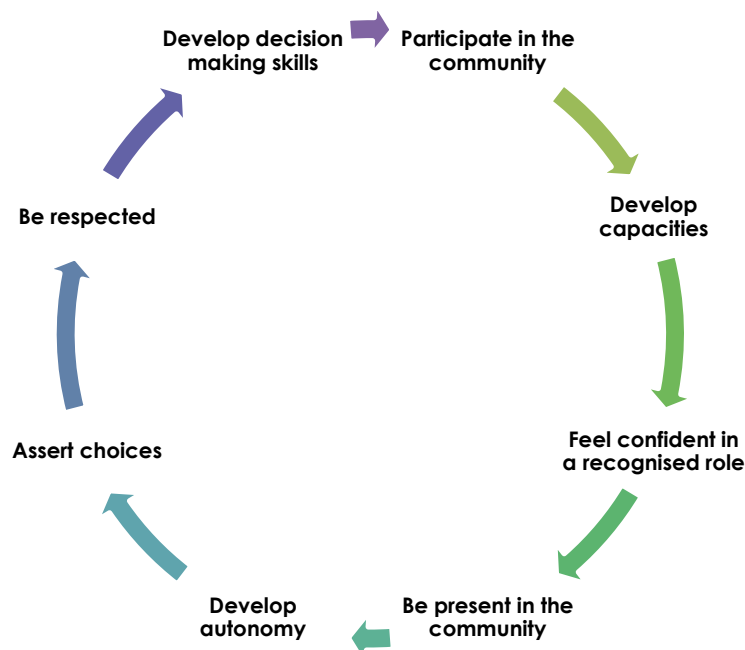
- Provide them with information and assist them in learning more about how the person is supported to make their own decisions;
- Listen to the family member and support them in finding solutions together with the person with an intellectual disability;
- Give them confidence in the capacity of their relative outside their home and outside a protected environment;
- Support them with more effective and creative ways of coping with problems linked to legal capacity, such as discrimination
- Support them in rejecting guardianship orders
- Put them in contact with peers.



**Supporters outside of the family can also play an important mediating role.** They can:

- Support families to accept the wishes and needs of the person with intellectual disabilities;
- Support the choices and decisions of the person with intellectual disabilities and help empower them to assert these towards their family members;
- Support actions to help the person with intellectual disabilities to gain friendships and membership in the community (for example a support network/circle) so that the family is not acting alone.

**Together families, supporters and service providers can facilitate the autonomy of persons with intellectual disabilities and support them in exercising their rights, including the right to legal capacity and to access to justice.**



b. **The role of families in case of conflicts with actors**

**Tips for trainers / Discussion**

*Discuss possibilities to support families in case of conflict with other actors. (Use flipchart or post-its to capture your ideas).*

*Objective: To propose options and ways to support family members, when there is a conflict with other actors.*

Sometimes persons with intellectual disabilities have conflicts with other actors, such as:

- Service providers;
- Social workers, educators, carers and other support staff;
- Legal guardians.

These conflicts may be related to various situations and **families have an important role to play to ensure that the rights of the person have not been violated**. Families should be encouraged to:

- Listen to the person, relying also on behaviours and other forms of communication, to understand the situation;
- Be aware and support the person in identifying rights that may have been violated;
- Support the person to seek assistance with self-advocacy organisations, legal aid services, the national ombudsman, etc. in case rights have been violated or are in danger of being violated;
- Support the person in asserting their legal capacity;
- Participate regularly in training so as to be up to date on how best to support the legal capacity of the person.

### ***Tips for trainers / Card game***

*Conclude the session, by using the card game to discuss a few of the more difficult scenarios.*

### **3. BIBLIOGRAPHY AND RESOURCES**

"Maximizing Legal Capacity : The Challenge for families", Ines Elvira Buraglia de Escallon. Available on <http://inclusion-international.org/wp-content/uploads/2013/10/6.Family-perspective-august-13-Finalppt.pdf>

"Role of families in Inclusion", Iona Kundu, Mentaid. Available on <http://chai-india.org/wp-content/uploads/2012/12/Role-of-parents.pdf>

"The family dimensions of the UNCRPD", Coface Disability. Available on <http://www.coface-eu.org/en/Publications/The-Family-Dimension-of-the-UNUNCRPD/>

"Charter for family carers", Coface Disability. Available in Bulgarian, English, French, Italian, Slovak and Spanish: <http://www.coface-eu.org/en/Publications/Charter-for-Family-Carers/>

Coface position paper : [http://www.coface-eu.org/en/upload/04\\_Policies\\_WG2/2011%20COFACE-D%20FamilyDimensionUNUNCRPD%20en.pdf](http://www.coface-eu.org/en/upload/04_Policies_WG2/2011%20COFACE-D%20FamilyDimensionUNUNCRPD%20en.pdf)

*Resources on family leadership & peer to peer support :*  
<http://www.belongingmatters.org/#!members-lounge-leadership/c9fr>

<http://www.parent2parentqld.org.au/personal-stories/personal-stories.php>

*In French*

"Les Aidants familiaux en France", BVA/Novartis, Available on [http://www.aidants.fr/images/stories/fondsdoc/AidantsFamiliaux\\_EtudeBVA\\_Novartis.pdf](http://www.aidants.fr/images/stories/fondsdoc/AidantsFamiliaux_EtudeBVA_Novartis.pdf)

CREAI Rhône-Alpes 2009: "Les besoins et attentes des aidants familiaux de personnes handicapées vivant à domicile". Available on [http://www.creai-ra.com/documents/creai2009\\_aidantsfamiliaux\\_cg69.pdf](http://www.creai-ra.com/documents/creai2009_aidantsfamiliaux_cg69.pdf)

### ***Tips for trainers***

*Please include possible resources at national level*

## VIII. Personalising support - How can we support persons with intellectual disabilities to have more control and choice in their everyday life?

### **Tips for trainers:**

*Have a person with intellectual disability co-deliver the training module. Cooperate with self-advocacy groups.*

*If this is not possible, invite person with intellectual disability to share a life story.*

*If this is not possible, find a video story in your own language / from your own country.*

*If this is not possible, use Kate's and Joseph's story.*

### OBJECTIVES OF THE MODULE

- Give information and tell **real life stories** for supporters of legal capacity so they have a **better understanding for the real lives** of persons with intellectual disabilities and their **support needs in everyday lives**
- Give information and training about **person-centered planning ideology and tools**
- Give information about the **new ways of providing personalized support** and develop services

### KEY MESSAGES OF THE MODULE

- Person centred planning is a process of continual listening and learning. It focuses on what is important to someone now and for the future; and acting upon this in alliance with their family and friends.
- It is not simply a collection of new techniques. Person-centered planning is not a service plan, it is not based on organisational needs or professional evaluations. It does not replace supported decision-making. It is based on a completely different way of seeing and working with people with disabilities, which is fundamentally about sharing power and community inclusion.
- Person-centred planning and self-directed support supports people to make informed choices, communicate their desires, plan for the future and advocate for themselves.

### LESSON PLAN OF THE MODULE

Recommended length: 2 hours

Item	Tool	Timeframe
Introduction & warm-up	Your strength by drawing*	15 min.
Real life story	1. Presentation* or 2. Video-story: Kate's story	20 min.
Discussion on barriers of choice and control	1. The European Agency for Fundamental Rights study 2012 or 2. KVPS Expert Group materials with photos*	15 min.
Introduce Person-centred planning ideology and tools	1. Mini-book* or 2. One Page Profile	30 min.
Introduce Self-directed support and tools	Video story: Kate's story	15 min.
Good example of personalising support	Video story: Joseph's story	15 min.
Conclusion	Drawing made by John O'Brien: What is – What can and should be*	10 min.

\* Co-training by persons with intellectual disabilities is encouraged.

## 1. CHOICE AND CONTROL OF PERSONS WITH INTELLECTUAL DISABILITY

The European Agency for Fundamental Rights studied the experiences on **choice and control** of persons with intellectual disabilities and people with mental health problems in nine countries in Europe (2012).

The study found that people with intellectual disabilities:

- often cannot choose where to live and who to live with
- often have difficulties when they want to live in the community as there are not many apartments where they can live on their own or with the support they choose
- often live in institutions and care homes and often do not have privacy or are treated with respect
- do not have enough money to rent or to buy somewhere to live on their own
- have problems finding paid jobs and are often treated unfairly or discriminated against
  - separate schools for persons with disabilities do not give them the skills they need to find work
  - many employers do not give them a chance
  - by the nature of many work places that are difficult for them to work in, for example, information is not available in an easy read format
- often cannot vote or do not know how to take part in politics.
- are prevented by laws from making choices and deciding what to do
- find little official information in an easy read format
- find the law and courts difficult to understand

One way to support person with disabilities to have more choice and control over their lives is personalized support. We can use and develop person-centred planning and self-directed support so that people with intellectual disability can **maximise choice and control** in their lives.

Person-centred support is not just a box-ticking exercise and it does not replace supported decision-making. When using person-centred planning, the supporter helps the person with disabilities to express their wishes and to put in place a plan so they can realise their goals and dreams.

## 2. PERSON-CENTRED PLANNING TOOLS AND PERSONALISED SUPPORT

What is person-centred planning and how it can be used alongside supported decision-making and legal capacity?

Person centred planning is a process of continual listening and learning. It focuses on what is important to someone now and for the future; and acting upon this in alliance with their family and friends. It is not simply a collection of new techniques or a box-ticking exercise. It does not replace supported decision-making. It is based on a completely different way of seeing and working with people with disabilities, which is fundamentally about sharing power and community inclusion.

Key features of person centred planning:

- 1) The person is at the centre. Person centred planning is rooted in the principles of shared power and selfdetermination. People using person centred planning make a conscious commitment to sharing power.
- 2) Family members and friends are partners in planning. Person centred planning puts people in the context of their family and their community.
- 3) The plan reflects what is important to the person, their capacities, and what support they require.
- 4) The plan results in actions that are about life, not just services, and reflect what is possible, not just what is available.
- 5) The plan results in ongoing listening, learning, and further action.

Person-centered planning is not a service plan, it is not based on organisational needs or professional evaluations. Person-centered Planning is not about doing things to the person or for the person.

Person-centred planning is a way of discovering what people want, the support they need and how they can get it. It is evidence-based practice that assists people in leading an independent and inclusive life. Person centred planning is both an empowering philosophy and a set of tools for change, at an individual, a team and an organisational level. It shifts **power** from professionals to people who use services.

Real person-centred planning:

- Focuses on the person's gifts and tries to use them
- Starts by focusing upon what is most pressing for the individual
- Gives most emphasis to **the voice of the persons** themselves and to those who love them
- Helps people use of their networks and their community
- Let's friends and family be much more involved
- Doesn't care about sticking to rules, it is creative and flexible
- Is organised to suit to the person and their community
- Puts the person in charge

Person-centred Planning is about working with someone to find out what they want to do with their life and working out how to make it happen. It is very different from a 'care plan' or 'assessment' that looks at what a person can or cannot do. Person-centred planning is planning for something – it's about taking some action, making changes. It should see the person as a citizen and community member, not just a service user.

There is a danger that persons with intellectual disabilities are not in charge and they are only seen as passive recipients of services. Then person-centred planning is just another thing that the system provides to them. Culture change is a long-term effort. Our service systems often view people through diagnosis and describe people in terms of their deficiencies. People get treated as one of 'them'. Services, service organisations and funding are built around categories of people and standard service models.

Person-centred planning presents a challenge to this mindset – it is a lever for change in people's lives, services and communities. Person-centred planning - at its best - supports people to make informed choices, communicate their desires, plan for the future and advocate for themselves.

The foundation for person-centred planning is a range of simple, practical person-centred thinking skills and tools. Using these tools can bring immediate **changes to people's lives** and to the way professionals and staff supporting people work.

These tools include: 'MAPS', 'PATH', 'Important to/Important for', 'Relationship Circle' and 'Decision Making Agreement.' See <http://www.helensandersonassociates.co.uk/> Each tool is based on the same principles: all start with who the person is and ends with specific actions to be taken.

'MAPS' and 'PATH' are developed by Judith Snow, Jack Pearpoint and Marsha Forest with support from John O'Brien and others. 'MAPS' and 'PATH' focus on desirable future or dream. 'MAPS' is based on questions: What is the person's history or story? What are his/hers dreams? What are his/hers nightmares? What are his/her strengths, gifts, and talents? What is the plan of action? The action plan is about working towards the dream and away from the nightmare. Maps can be used as a starting point with an individual who feels comfortable with dreaming, who already has people to support him/her and who wishes to have some changes in his/her life.



"My life, my map"  
Kuhmo, Finland 2010

One example of a person-centred tool is the 'One Page Profile'. A 'One Page Profile' captures all the important information about a person on a single sheet of paper under three simple headings; What people appreciate about me? What's important to me? How to support me best?



A person may have more than one profile depending on the purpose of the profile. A One Page Profile is good to use to prepare transitions. One Page profiles are the starting point to gathering person-centred information. Profiles need to be reviewed and updated regularly.

One page profile

**Photo**

Each one page profile has a current photo of the person.

**Appreciations**

This section lists the positive qualities, strengths and talents of the person. It can also be called "like and admire".

**What's important to the person**

This is a bullet list of what really matters to the person from their perspective (even if others do not agree). It is detailed and specific. This section needs to have enough detail so that someone who does not know the person can understand what matters to them. It could include:

- Who the important people are in the person's life, and when and how they spend time together.
- Important activities and hobbies, and when, where and how often these take place.
- Any routines that are important to the person.

**How to support the person**

This is a list of how to support the person, and what is helpful and what is not.

The information in this section includes what people need to know, and what people need to do.

**Tips for trainers / Exercise:** Participants practice using a person-centred planning tool. Please ask participants to make their own 'one page profile.'

The purpose of a **one-page profile** is to provide a summary of **person-centred information** that people in the person's life can use to:

1. get to know them quickly,
2. ensure that they are providing **consistent support in the way that the person wants**

The one-page profile opens the way to conversations with a person about what is working and not working in their life.

<http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-thinking/one-page-profiles.aspx>



Successful implementation of a person-centred planning is not that more people have plans. More people have to have plans which make a difference. After successful implementation the person has a stronger sense of his/her own dream, a stronger belief that things could be different and that he/she can make his/her own decisions. The people around the person will have a clearer shared understanding of what kind of a person he/she is and a stronger shared commitment to working with him/her to make a difference.

### 3. NEW WAYS OF PROVIDING PERSONALIZED SUPPORT - SELF-DIRECTED SUPPORT (INFORMATION AND EXAMPLES)

**Tips for trainers**  
Show the following video and discuss with participants. Kate's story: Kate has used an individual budget to employ a support worker so she can live independently in her own home.  
<https://www.youtube.com/watch?v=dvjPoHq9m0A>

When person-centred planning is combined with an upfront (indicative) allocation of money (a personal budget), it is called support planning. Person-centred thinking will benefit anyone assisting in support planning for people who are making decisions about how they want to live.

**Self-directed support** is an approach to care, support or independent living that gives people the optimum choice and control over their support arrangements. Self-directed support is a system of funding for support that helps people with disabilities, families, older people and many other disadvantaged groups to achieve full and active citizenship.

People and their lives, needs and aspirations are different. Service system tends to narrow the choices for support for persons with disabilities in steady, fixed services. Often there are no wide options of support arrangements to choose from, and not enough inclusive options. Person-centred planning isn't enough, if there are no real choices or they are always similar to everybody.

With the model of self-directed support, the person with disabilities is put in the middle of planning and organizing services, and support is arranged as flexible as possible around the person, according to his real support needs and aspirations.

Self-directed support allows people, their families and their carers to make informed choices on what their support looks like and how it is delivered, making it possible to meet agreed personal outcomes. Support and care have a vital role to play in ensuring everyone can enjoy the same human rights - dignity, equality of opportunity and access. Having greater control of your life and decision making leads to improved wellbeing.



"My Self- Directed Support "  
Pornainen, Finland 2013

Support is self-directed when..

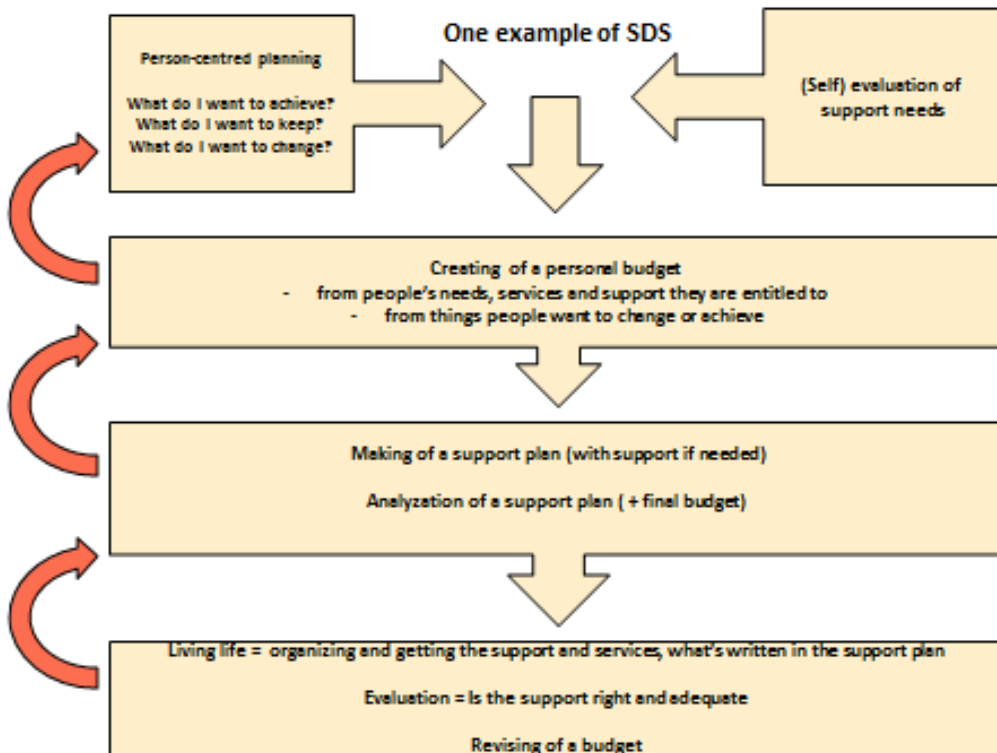
- person himself/herself work together with the circles of support to get support that's right for him/her
- person is treated with respect by the professionals working with him/her
- person is given help to understand the choice he/she has and is able to decide what choice to make
- professionals helps him/her to look at new and different

ways to support him/her and live life that he/she wants

- person is involved in deciding how his/hers support is planned and arranged
- person is supported to take part in the life of the community
- a person is given as much control over his/her support as he/she wants and that a person uses that control responsibly
- support helps him/her feel safe and secure, but also allows him/her to take some risks that are necessary for him/her to learn new skills or do new things



**ATTENTION!** A supporter facilitates person-centred planning. The person with a disability is the pilot of this process, the supporter does not plan for or instead of the person concerned.



Rajalahti 2014

Experiment in Finland (2014) showed that process of person-centred life-planning can improve the sense of well-being, because the disabled service-users are able to think about improvements in their lives. Some have had the opportunity to make profound changes in their lives with the help of the process of personal budgeting. Positive experiences are useful when developing the system of self-directed support. However, the research results concerning the impact of institutional power relations in the lives of disabled people indicate, that the practice of personal service-planning doesn't necessarily improve opportunities for self-determination, if professional power remains profoundly influential.

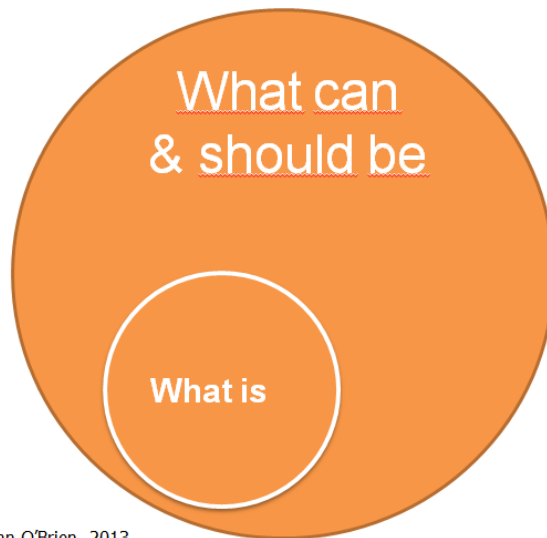


"My Self- Directed Support"  
Vantaa, Finland 2013

**Tips for Trainers**

Show the following video and discuss with participants. Joseph's story: Caroline Tomlinson talks about how a personal budget has helped her son Joseph  
<https://www.youtube.com/watch?v=1DrQw8JNlLw>

#### 4. CONCLUSION



John O'Brien, 2013

#### **Tips for Trainers**

*Use this picture made by John O'Brien to finalise the module. Have a conclusion and shared discussion. What is the situation of personalised support at the moment in your country for persons with intellectual disabilities? What can and should be? How participants can make a difference? What this means in your services / your work / your life?*

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(English) Joseph's story :<https://www.youtube.com/watch?v=1DrQw8JNILw>

(English) One page Profile <http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-thinking/one-page-profiles.aspx>

## IX. Changing the mindset

### OBJECTIVES OF THE MODULE

- Understand the importance of Article 8, its main provisions and its connections to earlier Articles.
- Understand how private persons and entities, especially professionals supporting persons with intellectual disabilities can become active in the awareness-raising.

### KEY MESSAGES OF THE MODULE

The elimination of social exclusion concerning the persons with disabilities requires profound changes to be made in the public opinion about disabled persons.

In order to achieve this, the participating states assumed various obligations in Article 8 of the Convention to dismantle the negative social stereotypes surrounding people with disabilities.

The best antidote to prejudice is raising awareness of intellectual disabilities, sensitizing and information activities. This activity should be continued as widely as possible, leveraging scenes of social life such as the media and education, community life and employment.

It is important that awareness-raising events, campaigns, sensitizing programs convey a true image of the mentally disabled people, introducing their values and value-creating abilities to the world.

### LESSON PLAN OF THE MODULE

Recommended length: 2 hours (120 min)

Item	Tool	Timeframe
Introduction, overview of article 8 of the convention	Presentation *	10 min.
- public awareness	Presentation (5 min) videos + discussion (15 min)*	15 min.
- the human rights model	Presentation (10 min) role play for 3 persons + discussion (10 min)*	20 min.
- promoting positive perceptions	Presentation (5min)*	5 min.
- promoting inclusion at the workplace and the labor market	Presentation (5min) open discussion (5 min)*	10 min.
- fostering respect for Pwid in the education system	Presentation (5 min) individual exercise (15 min)*	20 min.
- the role of media	Presentation (5 min) brainstorming exercise (5 min)*	10 min.
- promoting awareness-training programs	Presentation (5 min) brainstorming exercise (5 min)*	10 min.
Prejudice and discrimination	Presentation (5 min) discussion (5 min)*	10 min
Facing up challenges, conclusion	Presentation (5 min), discussion (5 min)*	10 min

\* Co-training by persons with intellectual disabilities is encouraged.

## 1. INTRODUCTION

The UNCRPD, is an international convention, which defines obligations for States Parties. Private individuals and entities are not subject to the convention. However, the UNCRPD is not only a legal instrument, but also a **political message**, which expresses a commitment to the social integration of persons with intellectual disabilities. It is obvious that this agenda cannot be implemented exclusively through governmental activity: the involvement of other actors in society is also required.

The social inclusion of persons with intellectual disabilities demands a **radical change of the public mindset**. Article 8 of the UNCRPD prescribes a set of obligations for States Parties in order to counter the negative stereotypes about persons with intellectual disabilities. Private persons and organisations are to be encouraged to participate in this process. First and foremost **professional supporters of persons with intellectual disabilities** are expected to treat their clients according to the highest ethical standards, reflecting the social model of disability, as represented by the UNCRPD. These expectations should also form a pattern for others: employers, teachers, service providers etc.

This module describes the concept of the UNCRPD on the appropriate treatment of PwD consciously respecting their human dignity (Article 8). Article 8 has strong links with some general principles and other basic rules of the UNCRPD. Article 8 has to be interpreted in the light of these latter rules, which are analysed under sections VII.2 to VII.4.

## 2. OVERVIEW OF ARTICLE 8 OF THE CONVENTION [AWARENESS-RAISING]

### a. Public awareness

Outdated models of support for people with intellectual disabilities and discriminatory attitudes have meant that society has not accepted them and has not recognized that it needs to change.

The UNCRPD encourages States Parties to seek to change public attitudes by promoting positive images of persons with intellectual disabilities and commissioning campaigns and media activity to challenge stereotypes. This could be complemented by smaller, community-based activity to build personal relationships between persons with and without disabilities.

#### ***Tips for the trainers***

*The exercise has the following objectives: to present positive examples of the awareness raising, sensitizing and information providing activities being in compliance with the goals and principles of the Convention that are showcasing an authentic view of the disabled, introducing their values and the difficulties they face in the world.*

*Watch together at least one of the following videos. An example for a bigger awareness campaign for the inclusion of persons with intellectual disabilities: [https://www.youtube.com/watch?v=yIkwM75A\\_WU](https://www.youtube.com/watch?v=yIkwM75A_WU)*

*An integrated performance by Hungarian artists with and without intellectual disabilities ('I don't give up'): [https://www.youtube.com/watch?v=skvqx\\_D\\_YPKM](https://www.youtube.com/watch?v=skvqx_D_YPKM)*

*If there are videos of national good practices available on the Internet in the course of the training, it is strongly recommended that the trainer introduces them.*

*Then discuss the videos.*

## b. The human-rights model

The UNCRPD, echoing the human-rights model of disability, confirms that people with intellectual disabilities should not be pitied and classified as passive recipients of charity. It affirms that people with an intellectual disability are entitled to **enjoy full social citizenship, and all human and citizen rights**. Respect for the rights identified in the UNCRPD is a duty of all States Parties, private persons and entities.

Professionals supporting persons with intellectual disabilities are expected to treat their clients **as subjects with rights and duties**. They have to utilize a service-provider attitude, in which both parties have rights and obligations, rather than a subordinating one. The supporting position of the professional is not established by power or authority, but by competence and responsibility.

### **Tips for the trainers**

*The objective of the exercise is to make the participants understand that it is important for professionals (in this exercise: doctors) dealing with intellectually disabled people to consider their clients as persons subject to rights and obligations, and not as subjects for charity or guardianship. The training helps the participants understand that it is essential for changing the attitude towards people with disabilities that the professionals dealing with them and their professional and natural environments treat them as partners and full-fledged citizens.*

*Role Play for 3 persons + discussion*

*Anne S. is the supporter of Zoe C., a middle-age woman with intellectual disabilities. Anne S. is accompanying Zoe C. to the doctor (George H.), because Zoe C. has recently had terrible headaches. During the examination George H. (doctor) talks to Zoe C. and gives her instructions as if she were a child. After the examination George H. (doctor) talks exclusively with Anne S. (supporter) on the diagnosis and therapy. How can A effectively influence the way that George H. (doctor) engages with Zoe C.?*

*After the role play of the situation, have a discussion involving all participants.*

## c. Promoting positive perceptions

Common popular stereotypes often generalize and write off the potential of persons with intellectual disabilities considering them unable to work or create any marketable value. Potential employers tend to give them no opportunity to prove their working capabilities. Laws that are well intentioned can often be over protective, restricting opportunities for persons with intellectual disabilities.

## d. Promoting Inclusion at the workplace and in the labour market

Professionals supporting persons with intellectual disabilities are expected to help their clients develop **self-esteem**, and where appropriate help the individual to develop work competencies. States parties should commission and publicise **Research** to challenge these negative views and increase awareness of the performance capabilities of persons with intellectual disabilities.

### **Tips for the trainers**

*The objective of the exercise is to help the participants gather experiences about how the intellectually disabled people can fit into the labor market, which is one of the most important scenes of integration. The objective of the exercise is to confirm once again that persons with disabilities are not subjects of charity, but with proper support and social acceptance they are able to carry out valuable work just as the rest of society.*

### **Open discussion.**

*Have you ever heard in your country about protocols estimating the working abilities of persons with intellectual disabilities? What do you know about these methods?*

*Are there NGO's in your country operating these protocols, and helping job-seekers with intellectual disabilities to find a proper job?*

*The following website introduces an internationally known and applied protocol of working ability estimation: [www.lantegi.com](http://www.lantegi.com). (Available also in English.) Watching a few video clips from this site is recommended.*

### **e. Fostering respect for persons with disabilities in the education system**

Nurturing an inclusive societal attitude should start at the possibly earliest age. The best way is the **integrated education** of children with and without disabilities. It should be stressed, however, that integration includes more than the education of these two groups of children at the same location. Namely the mutual respect of the differences and common work with children with diverse capabilities as well as family and social backgrounds require good professional skills, careful preparation, and the involvement of parents, carers and supporters..

Where integrated education is introduced, there should be an emphasis upon children with intellectual disabilities gaining self-confidence being encouraged to become more independent and protecting them from bullying.

It is useful to make **contacts with schools attended by no or only a few child with disability**. Special programmes (e.g. theme-specific discussion class) in these schools may make pupils familiar with the world of persons with disabilities.

#### **Tips for the trainers**

*The objective of the exercise: Participants address the issue of educational integration of people with intellectual disabilities.*

#### **Individual exercise.**

*You have the opportunity to organize an awareness-raising discussion class in a primary school for 10-year-old pupils under the title 'Children with intellectual disability among us'. Prepare the lesson plan for the class (45 minutes).*

*Compare, contrast and discuss the lesson plans produced.*

### **f. The role of the media**

The different parts of the media often **depict persons with intellectual and psycho-social disabilities in a false, distorted way**. There can be an emphasis upon triggering feelings of pity and sympathy, reinforcing the out-of-date medical model of disability. Programme editors and interviewers often talk to persons with intellectual disabilities not as equal partners, but in an infantilizing manner. Supporters, who engage with the media, should object to such characterization.

Similarly in **modern literature, art** and especially in **films**, the image of persons with intellectual or psycho-social disabilities is usually rather negative. Aggressive, dangerous, abusive figures are over-represented.

This reinforces the stereotype that, referring to ‘the public danger’ they represent, these persons should be isolated from society, and should be put into old-type large psychiatric institutions, rather than receiving modern, community-based services. Supporters should draw attention to the harmful effect of this characterisation. For example, they could use **social media** to express their opinion about stereotyping, to publicise good news stories, and circulate factual, statistical information about the low incidence of cases where members of the public are injured or threatened by irrational behaviours.

### **Tips for the trainers**

*The goal of the practice: to emphasize how harmful it is if the media showcases an offensive and humiliating image of intellectually disabled people. What can be done for example against negative stereotypes, sarcasm appearing in a blog post?*

#### **Brainstorming exercise.**

*You are reading a blog post by a popular blogger in your country mocking a kid with Down syndrome. Several commenters find the post very funny. What can you do in this situation?*

## **g. Promoting awareness-training programmes**

An important task of professionals supporting persons with intellectual disabilities is to initiate awareness-raising training programmes for representatives of other professions, who they may have contact with. Examples of professionals who could be targeted include:

- judges, attorneys dealing with guardianship, employment, and education cases
- judges, public prosecutors, staff members of penal institutions, dealing with victims or perpetrators with disabilities
- clerks of guardianship authorities
- clerks of equal treatment bodies
- teachers and child care professionals
- Potential employers
- community service-providers
- supporters, and guardians.

### **Tips for the trainers**

*The exercise has the following objectives: to introduce the importance of the shaping of public opinion, sensitizing programs to professionals coming into contact with intellectually disabled people in their work. The exercise helps participants consider what themes the awareness raising and sensitizing training should include.*

#### **Brainstorming exercise.**

*Which issues should be primarily addressed in an awareness-raising training session for judges dealing with guardianship cases?*

## **3. PREJUDICE AND DISCRIMINATION**

**Prejudices** are thoughts, feelings and judgments, which associate additional negative characteristics with an individual or social group e.g. to intellectual disability. Discrimination flows from prejudice

There are two aspects of discrimination. The **social dimension of discrimination** covers the phenomenon that some social groups and minorities are traditional victims of



oppression, segregation and are not able to participate in social activity on an equal basis with others. This aspect of discrimination is a result of complex historical and contemporary processes.

The **legal dimension of combating discrimination** is defined by State Party laws according to quite similar principles, but the detailed provisions can differ. Discrimination can be direct or indirect. **Direct discrimination** exists, if somebody, in the course of their daily life suffers detrimental treatment due to his/her 'protected characteristic' (e.g. sex/gender, political, religious thoughts, ethnical adherence, disability or sexual orientation). **Indirect discrimination** exists if the detrimental treatment does not flow directly from the status of the person with intellectual disabilities but a seemingly neutral provision affects the protected group disproportionately more detrimentally than other ones. Non-discrimination laws punish this hidden type of discriminatory conduct as well. It shall be noted that the actual national legal norms determine the exact and detailed rules of discrimination in the legal sense.

Discrimination that can be challenged legally amounts only a small fraction of the total. Most discriminatory actions against persons with intellectual disabilities have their **roots** in **negative prejudices**. However, since the UNCRPD targets the eradication of **all forms of discrimination** against persons with intellectual disabilities, a primary mission of supporters should be to struggle against negative stereotypes and prejudices.

Demonstrating **discrimination against persons with disabilities is sometimes particularly difficult**, because perceptions about the abilities and/or capacities of persons with intellectual disabilities may appear to give some legitimacy to differential treatment. Requirements in some legislation for reasonable accommodation may also confuse matters. Clearly reasonable, proportional differential treatment based on real differences does not count as discrimination.

#### 4. FACING UP TO CHALLENGES

In summary the main challenges in changing society's mindset are:

- **negative prejudices** attaching supposed negative characteristics to any person with a disability.
- Prejudices can create a **vicious circle**: prejudices inspire segregation, and discrimination, which moves persons with intellectual disabilities away from the scenes of social activity. Lack of insight into the capabilities of persons with disabilities can lead to this knowledge gap being filled by prejudices.
- Attention should be paid to the fact that **people with disabilities are not an homogeneous** group. Persons with disabilities can have mutual prejudices against each other.
- **Primary remedies for tackling prejudice** are awareness-raising, information sharing and dissemination activity.
- These activities should reach the largest possible audience, utilizing communication tools like the media and education).
- awareness-rising activity should take place **in line with the purposes and general principles of the UNCRPD**.

Most importantly professionals supporting persons with intellectual disabilities must have a very clear grasp and understanding of the values of the social model of disability as affirmed by the Convention.

**Tip for the trainers**

*Advocacy Tools that supporters/service providers can use in their concrete situation.*

- *Advocacy toolkit: all the materials you need to support the UNCRPD:*  
<http://www.usicd.org/index.cfm/tools-and-resources>
- *Advocacy Tool Kit Skills and Strategies for Effective Self and Peer Advocacy:*  
<http://www.disabilityrightswi.org/wp-content/uploads/2008/02/advocacy-tool-kit-2007.pdf>

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<http://www.disabilityplanet.co.uk/critical-analysis.html> (on the media representation of persons with intellectual disabilities)

## X. Terminology and glossary<sup>13</sup>

**'Access to justice'** is a 'broad concept, encompassing people's effective access to the systems, procedures, information, and locations used in the administration of justice. Persons who feel wronged or mistreated in some way usually turn to their country's justice system. In addition, persons may be called upon to participate in the justice system, for example, as witnesses or as jurors in a trial. Unfortunately, persons with disabilities have often been denied fair and equal treatment before courts, tribunals, and other bodies that make up the justice system in their country because they have faced barriers to access. Such barriers not only limit the ability of persons with disabilities to use the justice system, they also limit their contribution to the administration of justice.'

**'Communication'** in terms of the UNCRPD 'includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.'

The term **'intellectual disability'** is variously defined. The UNCRPD states that disability 'includes those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'

Individuals who have the label of an intellectual disability can and should be described in many other ways including, friend, neighbour, relative, parent, colleague, community member, employee, employer and parent. They may have difficulty with certain cognitive skills, although this varies greatly among individuals. We adopt a progressive understanding that ability-disability is a continuum that all human beings exist on at various stages in our lives, where disability is an infinitely various but universal feature of the human condition. In keeping with international human rights law, as well as the standards set by leading advocacy organizations for people with intellectual disabilities, such as Inclusion Europe, we do not wish to define intellectual disability prescriptively. After all, definitions may vary in different countries and we wish to avoid being over- and under-inclusive in our use of the term.

Instead, for the purposes of this research we understand intellectual disability in the broad sense of the term as including those who may require intensive support in almost all aspects of their lives, and those who require support only in some areas, such as with financial administration. In other words, the AJuPID project draws on a definition of intellectual disability that encompasses a wide spectrum including people with a range of complex, profound, or relatively slight intellectual impairments and disabilities.

**'Legal capacity'** refers to both a person's legal standing (legal personality) but also his or her ability to act on such legal standing (legal agency). An oft-used example to illustrate this definition is voting. A person may hold a formal right to vote on an equal basis with others (their legal personality is upheld). Yet a lack of reasonable accommodation – such as ramps to enter polling stations, or plain language guides – may mean that a person cannot exercise their right to vote on an equal basis with others (their legal agency is denied).

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<sup>13</sup>terms of glossary is based on the study titled, "Comparison of legal systems in access to justice for persons with intellectual disabilities in the following countries: Bulgaria, Finland, France, Hungary" AJUPID project-2015.

Both elements – legal personality and legal agency – are required in order that a person has legal capacity on an equal basis with others.

**'Mental capacity'** is a concept used in ethics and law which asks that someone demonstrates 'independent' capacity to consider a range of options when deciding, to consider the consequences of different options, and to communicate a choice. When a person is deemed to lack mental capacity a substituted decision-maker is typically appointed by courts to make decisions on his or her behalf – typically using a 'best interests' standard to guide decision-making.

**'Procedural accommodation'** is a term used in Article 13(1) to refer to reasonable accommodation provided in justice systems to ensure 'persons with disabilities who intervene in the judicial system can do it as subjects of rights and not as objects of protection.'

**'Reasonable accommodation'** refers to necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms. According to the terms of the UNCRPD, 'discrimination on the basis of disability' (...) includes all forms of discrimination, including denial of reasonable accommodation.'

**'Substituted decision-making'** is a term used in international disability law to refer to the authorized appointment of someone to make a decision on behalf of a person who is deemed to lack the mental capacity to make a decision for him or herself. 'Substituted decision-making' typically occurs regarding decisions related to healthcare, lifestyle or financial issues, and are typically made according to what is perceived to be in a person's 'best interests.' The UNCRPD Committee defines 'substituted decision-making regimes' as follows:

Substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where (i) legal capacity is removed from a person, even if this is just in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will or (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective "best interests" of the person concerned, as opposed to being based on the person's own will and preferences.

**'Supported decision-making'** is one type of support to exercise legal capacity. Supported decision-making refers to a decision made by a person, on his or her behalf, with support from others in order to exercise his or her legal capacity.

A **'supported decision-making regime'** is a term used by the UNCRPD Committee to describe the overarching model of support in line with Article 12 of the UNCRPD. It includes various support options which give primacy to a person's will and preferences. Such a regime should provide protection for all rights, including those related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live, etc.) and rights related to freedom from abuse and ill-treatment (right to life, right to physical integrity, etc.). While supported decision-making regimes can take many forms, they should all incorporate certain key provisions to ensure compliance with article 12 of the UNCRPD, including being available to all, even those with complex communication and intensive support needs, and being 'based on the will and preference of the person, not on what is

perceived as being in his or her objective best interests.’ The regime should include readily available and accessible supports, including facilitating support for ‘people who are isolated and may not have access to naturally occurring supports in the community,’ as well as the right to refuse such supports. (A more complete definition of a ‘supported decision-making regime can be read in the UNCRPD Committee’s first General Comment).

**‘Support to exercise legal capacity’** refers to the obligation on States Parties set out in Article 12(3) of the UNCRPD so that persons with disabilities can exercise their legal capacity on an equal basis with others. ‘Support’ is not specified in Article 12(3) but according to the UNCRPD Committee it ‘encompasses both informal and formal support arrangements, of varying types and intensity.’ Hence, support to exercise legal capacity is broad, and could include personal advocacy, plain language aids in court proceedings, accessible education, and so on.

AJUPID (2016) Adrienn Gazsi, Ákos Pordán, Albena Boteva, Caroline Looney, Claire Martinet, Eilionoir Flynn, Lisa Lopes, Liz Brosnan, Marie Gautier, Mariyana Branzalova, Martha Stickings, Maura O'Loughlin, Nele Verbrugghe, Oana Girlescu, Patricia Scherer, Petra Tiihonen, Philippe Colombe, Sabrina Ferraina , Sirkka Sivula, Szilvia Halmos