

**UN Convention on the Rights
of Persons with Disabilities**

Reference Document of Project



IDEA 12

2017

INCLUSIVE TRAINING ABOUT ARTICLE 12

www.idea12.eu



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1 Table of contents

1	Table of contents	2
2	Introduction	4
2.1	Who we are	5
2.2	Purpose of the Reference document	7
2.3	About the project IDEA 12	7
2.4	Inclusiveness as the leading principle of the project IDEA 12	8
2.5	Structure of the document	8
3	Supported decision-making, legal capacity, and needs for change in the-existing practice	10
3.1	Decision-making and legal capacity	10
3.2	Historical concept of legal capacity does not work for people	10
3.3	Paradigm shift in legal capacity concept	11
3.4	The Right to legal capacity – end of legal capacity restrictions	11
3.5	The Right to individual support in decision-making and exercising legal capacity	12
3.6	The Right to be safe in exercising legal capacity	13
3.7	The Right to universal design and reasonable accommodation	13
4	Significance of Article 12 of the CRPD for social inclusion and fighting discrimination of persons with disabilities	14
5	Educational goals of training about Article 12 of the CRPD	15
5.1	One-day training	15
5.2	Three-day training and educational goals	15
6	Training topics	17
6.1	Implementation of Article 12 in the EU	17
6.2	Implementation of Article 12 in the states of the IDEA 12 project partners	17
6.3	What difference Article 12 makes in the lives of people with disability	17
6.4	Paradigm shift in the concept of legal capacity	18
6.5	Support in decision-making in relation to legal capacity	19
6.6	Degree of support in decision-making	20
6.7	Who can provide support in decision-making and exercising legal capacity	22
6.8	Process of providing support in decision-making (3 day training only)	23
6.9	Forms of support	24
6.10	Key tools for decision-making support (3 day training only)	24
6.11	Four important elements of supported decision-making	29

6.12	Reasonable accommodation.....	29
7	Acknowledgment	30
8	References	32
9	Attachment No 1: The status of implementation of SDM and reasonable accommodation (reports provided by project partners)	33
9.1	The Czech Republic.....	33
9.2	United Kingdom.....	34
9.3	Latvia.....	36
9.4	Lithuania	38
9.5	Slovakia	39
9.6	Spain	41

2 Introduction

Dear Readers,

We would like to focus on recent developments in our societies in the field of disability, namely, the shift **from the “best interest” model to the perspective of “rights, will and preferences” of people (with disabilities)**. It is not new to say that we all are equal in dignity and rights. What is new is the Convention on the Rights of Persons with Disabilities (hereafter CRPD or Convention) which makes it an obligation for states to guarantee equality in rights and dignity as a reality for all citizens.

With respect to equality, recognised by the Convention, we hold the following positions:

- **Position** that it is both necessary and possible **to meet in practice the requirements of the Article 12 CRPD** called, “Equal recognition before the law”.

That means also that people with learning disabilities, people after brain injuries, with dementia, mental health problems etc.

- can enjoy **legal capacity** on an equal basis with others in all aspects of life,
- have access to the **support** they may require in exercising their legal capacity,
- are **safe** on an equal basis in exercising their legal capacity
- can **live independently** and are **included in the community** (see Article 19 of the CRPD).

- **The Position of supported decision-making** (diversity, inclusion and participation).

We believe that all individuals are different, that we are interdependent and that nobody decides about us without us. We all are able to make decisions if there is a possibility to choose between at least two options. Some decisions are more difficult. Then, we might need support – from our family, friends, colleagues, neighbours. If we have a disability, we might need our supporters to be officially recognised by the law.

- **The Position of the witness** (open eyes and open mind to different experiences).

We know that all people are free according the Charter of Fundamental Rights and Freedoms and that they can act according to their rights, will, and preferences. We also know that in spite of it some of us live in the context of oppression. We witness it, reflect it and and we name it.

- **The Position of responsibility and comprehensibility.**

Our training teams represent two partners each from different worlds – one of them is a person with a “disability”, and the other, is a non-disabled person. In our teams, trainers are people who have different background, experiences and interests. We have the same aim: to implement article 12 of CRPD in a responsible, understandable and inclusive way. We all are open to learning. We need to learn not to hold onto, but to share responsibility and to take responsibility for one’s own life. We also need to appreciate different life experiences of others, and try to understand them. Each of us has personal responsibility for the

contribution to this aim. We can all change ourselves and “be the change we want to see in the world”.

We value diversity, inclusion, participation, responsibility, awareness of power structures, experiences, open-mindedness and understanding.

What we wish to do:

We would like to promote understanding of Article 12 of CRPD and supported decision-making. Training courses can be a good way to get a better understanding for both the trainers and the participants. We will deliver training in pairs. One half of the trainers are people with experience of living with disability. They know personally what it means when somebody challenges your legal capacity. The other trainers are people without apparent impairment who have other experiences. Together we have knowledge, skills and values making us competent pioneers ready to teach.

Together, we shall learn and teach how to make our common environment more understandable, providing equal opportunities and comfort for all sides. We will use the Good and Promising Practice Guide and the Handbook of Trainers.

2.1 Who we are

The IDEA 12 project is delivered by a partnership of the following organisations:

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<http://www.idea12.eu/national-trainers/>

The document was prepared by 'Quip' with substantial support from the other project partners and feedback from further persons and organisations named in chapter 6. The illustrations were designed by Ester Ortega Collado.

2.2 Purpose of the Reference document

States Parties to the Convention have agreed *“to promote the training of professionals and staff working with persons with disabilities in the rights recognised in the Convention so as to better provide the assistance and services guaranteed by those rights.”*¹ In most countries, lawyers and social workers don’t receive any training on the CRPD; this urgently needs rectifying.

This reference document is intended to be a frame of reference for preparing an inclusive training about Article 12 of the CRPD and about supported decision-making. An easy-read summary is being developed for trainers who may find reading difficult. The reference document can serve for anyone who would like to prepare similar training in the future.

The reference document is followed by two other documents: a *“Good and Promising Practice Guide”* and **‘A handbook for trainers of inclusive training’** which will contain tips for designing the learning format, strategies and activities, and identifying course materials and resources. Both documents were developed during the course of the project.²

The Reference document was developed as part of the project *“Inclusive Direction in Education of Adults on Article 12”* (acronym is IDEA 12) funded by the European Union. In addition to project participants, twelve organisations outside the project were involved in the development of the Reference document, providing feedback on the initial draft. (For the list of consulting organisations see chapter 6).

Awareness about Article 12 and its implementation is continuously developing. At the same time, we believe this material could still provide valuable help to organisations and individuals who strive for better conditions and equality in the lives of people with disabilities.

2.3 About the project IDEA 12

The leading idea of the project comes from observations of the UN Committee on the Rights of Persons with Disabilities (hereafter Committee) that *“across the European Union, the full legal capacity of a large number of persons with disabilities is restricted”* and *“capacity-building and training materials, public campaigns, statements and other documents published by the European Union institutions are not available in accessible formats”* (United Nations, 2015: 4, 5).

Shifting the paradigm from substitute decision-making to supported decision-making may be enhanced by raising awareness about the right to full legal capacity and assistance with exercising this right. According to the Committee, existing **awareness-raising** strategies are *“not continuous, do not include all institutions and staff and exclude certain groups of persons with disabilities”*. The report specifically named persons with learning disabilities and mental health problems (United Nations, 2015: 4).

The problem identified by the Committee relates to poor awareness and access of people with disabilities to capacity-building and training. Project IDEA 12 aims to improve awareness and

¹ Article 4(1)(i)

² Link to the project web site: <http://www.idea12.eu/>

capacity-building and education by preparing an inclusive training on supported decision-making for professionals, public administrators, people with learning disabilities and mental health problems.

Our practical experiences show that different member states have different examples of best practice. This provides an opportunity for sharing experience, developing innovative approaches and products, and scaling up innovations within the project partnership.

2.4 Inclusiveness as the leading principle of the project IDEA 12

The Committee identified the problem of poor awareness-raising³ and access of people with disabilities to capacity-building and training. Our project responds to this problem by involving people with disabilities who have first-hand experience with using support in decision-making in both levels of training: as part of the team of trainers (trainers with disability who work together with trainers without disability) and as part of the target group for training about article 12.

We count on several aspects connected to direct participation of people with first-hand experience in training events:

- Higher credibility of the authentic, personal testimonies leads to a greater impact on the attitudes of participants.
- People with disabilities have the opportunity of directly influencing public opinion; resulting changes may be more in tune with what is important to people with disabilities and to strengthen control on their own affairs.
- People with disability as equal partners in training pairs serve as a model for attitudes towards people with disabilities. This may also lead to strengthening the will of policy-makers to involve people with learning disabilities and mental health problems in consultation processes.
- People with disability learn more about their rights and how to fight for their rights. This strengthens the role of people with disabilities in the process of changing old-fashioned models of support towards implementing of the Convention.

The project partnership will make use of the experience of two partner organisations – CHANGE people (UK) and TUYA (Spain). The leading principle will be the partnership approach to trainers with disability who, among others, will receive reimbursement equal to the reimbursement of other trainers.

2.5 Structure of the document

In the following two chapters, you will find a brief explanation of the subject of the training: supported decision-making, and Article 12 of the CRPD and its significance for social inclusion of people with disabilities.

Chapter 4 provides a definition of the learning objectives of two basic formats of inclusive training about Article 12: a one-day training event for a diverse group of people including self-advocates, family members, policy-makers, services' providers and academics; a three-day training event which

³ See Art. 8 of the CRPD

is more practice-oriented and intended specifically for people with disabilities and their supporters (mainly relatives and professionals).

Finally, chapter 6 summarises the topics not to be missed in training and/or raising awareness events about Article 12.

3 Supported decision-making, legal capacity, and needs for change in the-existing practice

3.1 Decision-making and legal capacity

The right to make decisions and have control over one's life is crucial for everyone. All of us navigate our lives through making decisions on daily basis – about small and substantial matters. Making decisions is interconnected with concepts of „legal capacity“. **Decision-making process may or may not result in a legal act⁴, while legal acts are always results of decision-making processes.**

3.2 Historical concept of legal capacity does not work for people

Historically, in many jurisdictions, when a person with disability was considered to lack mental capacity, the traditional answer **was to restrict their legal capacity⁵ and to appoint a guardian to act “in the best interest”** of the person. These systems are referred to as **“substitute decision-making” regimes**. The Council of Europe notes in its ‘Strategy on the Rights of Persons with Disabilities 2017-2023’ that, *“Substituted decision-making, including full guardianship regimes where persons are stripped of their personhood in the eyes of the law and of the society, still prevail in many member States.”* (Disability Strategy 2017-2023, 2016: 25)

*The denial of legal capacity to persons with disabilities led, in many cases, to them being **deprived of many fundamental rights**, including the right to vote, the right to marry and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty.⁶* However, restrictions of legal capacity often meant **losing the opportunity and the possibility of making choices in all areas** of life. Practical experiences show that being restricted in having control over one's life can have **serious consequences**: people do not have the opportunity to learn or maintain skills, to become responsible for their actions and their lives, they lose motivation for everyday activities and even for the whole life. It can also lead to rebellion usually labelled as “behavioural problems”. *“Guardianship, by definition, **decreases self-determination and can lead to a significant negative impact on physical and mental health, longevity, ability to function, and reports of subjective well-being.**”* (Wright, 2010 cit in Blanck and Martinis, 2015a: 3). Restrictions of legal capacity thus become an additional, unnecessary “disability” for the person.

Another serious and frequently occurring “by-product” of substitute decision-making is abuse and neglect of the people under guardianship. **Restriction of legal capacity is** then not only a **disproportionate intervention into the autonomy** of the individual, in practice **it fails to meet its core purpose which is to provide protection** to a person with disability.

⁴ Legal act is a decision that has legal effect.

⁵ The concepts of mental and legal capacity are defined later in this chapter 2.4.

⁶ Convention on the Rights of Persons with Disabilities, General Comment No 1 (2014), United Nations, Committee on the Rights of Persons with Disabilities, Eleventh session, 31 March – 11 April 2014 (GC)

3.3 Paradigm shift in legal capacity concept

Negative experience with restrictive legal capacity motivated people with disabilities, their families and experts in different fields to look for a new model which would respect the rights of people with disabilities. Supported decision-making models started to be developed. In line with modern social work concepts, they are based on principles of support and social inclusion. Collectively, these models promote the notion that, instead of additional restrictions, people need support in making their own decisions. In their view, support needs to be proportional and tailored to individual circumstances. In 2006, this concept was adopted by the Convention on the Rights of Persons with Disabilities, signed and ratified by most of the countries across the world. The Committee urged States Parties to replace “substitute decision-making” with the concept of “supported decision-making”. Crucial elements of the new concept are provided in the Convention, articles 12 and 5: **the rights: 1. to full legal capacity; 2. to support that people may require in exercising their legal capacity; 3. to effective safeguards to prevent abuse in exercising legal capacity; 4. to be provided reasonable accommodation.** Detailed explanation of the supported decision-making concept, legal aspects and content of Article 12 is provided by General Comment No 1 (2014) adopted by the Committee (hereafter, ‘General Comment’).

3.4 The Right to legal capacity – end of legal capacity restrictions

The General Comment states that, *“legal capacity is a universal attribute inherent in all persons by virtue of their humanity. Article 12 of the Convention affirms that all persons with disabilities have full legal capacity”*.⁷ In relation to autonomy, Article 12 is about enhancing persons’ control over their life, their confidence, and the sense that they can make meaningful decisions.

Legal capacity includes both: **capacity to have rights and capacity to act** (i.e. exercise legal capacity). *“Legal capacity to act under the law recognises a person as an agent with the power to engage in transactions and create, modify or end legal relationships.”*⁸

*“Legal capacity and mental capacity are distinct concepts. Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors including environmental and social factors. Under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.”*⁹ In traditional guardianship regimes *“the concepts of mental and legal capacity have been conflated so that where a person is considered to have impaired decision-making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently removed. This approach is flawed for two key reasons: (a) it is discriminatorily applied to people with disabilities; and (b) it presumes to be able to accurately assess the inner-workings of the human mind and, when the person does not pass the assessment, it then denies him or her a core human right — the right to equal recognition before the law.”* In this approach, *“a person’s disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the*

⁷ See GC par. 8

⁸ See GC par. 12

⁹ See GC par. 13

law".¹⁰ **Art. 12 of the CRPD**, however, "makes it clear that "unsoundness of mind" and other discriminatory labels are not legitimate reasons for the denial of legal capacity"¹¹. It **does not permit such discriminatory denial of legal capacity, but, rather, requires that support be provided in the exercise of legal capacity**".

General Comment makes it clear that, "the development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention".¹² It means that substitute decision-making regimes have to be completely abolished and replaced by supported decision-making systems.

3.5 The Right to individual support in decision-making and exercising legal capacity

Some people may need support to be able to make decisions and exercise their legal capacity. Article 19 of the CRPD provides access to support, including personal assistance, in any area necessary to live independently, included in the community, and to prevent isolation and segregation. **Article 12 of the CRPD** guarantees access to the support people may require in exercising their legal capacity. "**Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities.**"¹³

General Comment states that, "...'**support' in exercising legal capacity is a broad term.**"¹⁴ "**The type and intensity of support may vary significantly from one person to another due to the diversity of persons with disabilities.**"¹⁵ The support **has to be accessible to all**. The level of support needs cannot be an obstacle to using the support,¹⁶ and non-conventional ways of communication cannot be the reason to deny provision of the support. In some cases it might be difficult to ensure the will of a person is fully understood. Such difficulty, however, cannot be the reason to replace their will with the supporter's decision "in their best interest". The concept of "best interest" needs to be replaced by the notion of "best interpretation of the will, wishes and preferences".

Support in decision-making and exercising legal capacity can be provided within "**formal or informal arrangements**".¹⁷ States are obliged to provide measures for formal support. "**Persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions**".¹⁸ They may use **peer support** or **advocacy** (including self-advocacy support). Another form of support is **assistance with communication** which entails the development and recognition of diverse methods of communication including non-verbal forms of communication. "**For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time**

¹⁰ See GC par. 15

¹¹ See GC par. 13

¹² See GC par. 28

¹³ See GC par. 17

¹⁴ *ibid*

¹⁵ See GC par. 18

¹⁶ E.g. GC par. 29 (a) and (c)

¹⁷ See GC par. 17

¹⁸ *ibid*

when they may not be in a position to communicate their wishes to others”.¹⁹ All persons have the right to engage in advance planning, and support should be provided in the advance planning process.

Right to legal capacity also means that *“some persons with disabilities can only seek recognition of their right to legal capacity and may not wish to exercise their right to support”*.²⁰

The protection provided to people with disabilities within the supported decision-making framework **must respect** the rights, will and preferences of the person to the extent that it includes the *“right to take risks and make mistakes”*.²¹

Any support provided to persons with disabilities aimed at full enjoyment of human rights and social inclusion needs to respect their will and preferences. Decision-making and exercising legal capacity in day-to-day activities and in relation to serious matters can only be achieved once people are enabled to become agents of their own life.

3.6 The Right to be safe in exercising legal capacity

The third element of the supported decision-making concept is having **appropriate and effective safeguards** present in a system. The **primary purpose** of these safeguards is to secure the **respect of persons’ rights, will and preferences**. *“Support in the exercise of legal capacity should never amount to substitute decision-making”*.²² In order to accomplish this, the **safeguards must provide protection from** any kind of **undue influence or abuse**, both from supporters and third parties.

“In relation to adults, the “best interests” principle is not a safeguard which would comply with Article 12. The “best interpretation of will and preferences” paradigm must replace the “best interests” paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others”.²³ Practically, this means that supporters will strive by using appropriate tools like, for example, communication charts, to understand what the supported persons express through their behaviour (see chapter 5.12.4), or to understand the context of their decisions by considering the wider picture of the situation by using person-centred tools (e. g. chapter 5.12.4).

3.7 The Right to universal design and reasonable accommodation

Support in the exercise of legal capacity also includes **measures related to universal design and accessibility**. This requires private and public actors such as banks, financial institutions, medical doctors, and other services and facilities to provide understandable information, or professional interpretation, which would enable persons with disabilities to perform the legal acts required to open a bank account, conclude contracts or conduct other social transactions.²⁴ The definitions of *“universal design”* and *“reasonable accommodation”* are provided in Article 2 of the CRPD and the States Parties’ obligations on *“accessibility”* are stated in Article 9 of the CRPD.

¹⁹ *ibid*

²⁰ See GC par. 19

²¹ See GC par. 22

²² See GC par. 17

²³ See GC par. 21

²⁴ See e.g. GC par. 34

4 Significance of Article 12 of the CRPD for social inclusion and fighting discrimination of persons with disabilities

*“Article 12 is premised on the general principles of the Convention, as outlined in Article 3, namely, respect for the inherent dignity, individual autonomy — including the freedom to make one’s own choices —, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women; and respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities”.*²⁵

Article 12 of the Convention is often referred to as the “core” of the Convention. The right to legal capacity guaranteed in Article 12 is closely and inseparably connected to other rights stipulated by the Convention. *“Legal capacity is indispensable for the exercise of civil, political, economic, social and cultural rights. It acquires a special significance for persons with disabilities when they have to make fundamental decisions regarding their health, education and work”.*²⁶ Article 12 is linked to Article 16 which requires States Parties to take all measures to protect persons with disabilities, both within and outside their home, from all forms of exploitation, violence and abuse. Legal capacity is also tightly related to Article 19 on independent living and inclusion in the community. *“Legal capacity is the key to accessing meaningful participation in society”.*²⁷ The Committee in its Draft General Comment No. 5 (2017) notes that legal capacity and equal recognition before the law *“are the basis of the realisation of independent and community living for adults with disabilities”*²⁸. At the same time, people *“have to be a part of the community”* to fully exercise their legal capacity²⁹. Without available and accessible community services, facilities, in-home services and support, including personal assistance, real choices of residence, and other conditions stated in Article 19, there can be limited opportunity for exercising legal capacity leading to reduced suitable life choices.

Rights included in Article 12 have practical impact on the lives of people with disability. They lead to greater self-determination (Kohn et al., 2013 cit in Blanck and Martinis 2015b: 26) which implies being independent and included in the community, healthier, and able to recognise and resist abuse (Powers et al., 2012, cited in Blanck and Martinis, 2015b: 27). A true community integration means being integrated into all facets of the community, including the financial sphere (Martinis, Wohl, Mills, 2015: 8).

Practical examples of the positive impact legal capacity and equal recognition before the law can have on people’s lives are presented in the document Good and Promising Practice Guide.

²⁵ GC par. 4

²⁶ GC par. 8

²⁷ GC par. 13

²⁸ Draft General Comment No. 5 (2017) par. 26

²⁹ Draft General Comment No. 5 (2017) par. 78

5 Educational goals of training about Article 12 of the CRPD

In this chapter, we summarise the educational goals of the one-day and the three-day training on Article 12 of the CRPD. Both training formats will be inclusive with participants composed of people with different needs and abilities: people with disabilities, their families, support services' practitioners, university students and trainers, public administrators, policy-makers and the general public. The training will be delivered by two trainers, one of them a person with disability.

5.1 One-day training

The one-day training is intended for a larger group³⁰ with a mix of people: teachers and university students (mainly from social work and law), people with learning disabilities and mental health problems, their families, staff from support services, public guardians, and public administration and policy-makers. At the end of the training, participants shall embrace equal recognition before the law. The educational goals are that at the end of the training, participants will:

- Be aware of equality of people in dignity and rights.
- Understand the heart of the change: the paradigm shift from the “best interest” to the “rights, will and preferences”.
- Understand what implementing Article 12 of the CRPD means for people with disabilities and how it relates to other human rights covered by the Convention, e.g. independent living and community participation, and access to justice.
- Understand what implementing Article 12 means for my (participant's) specific role – what I can do for to support it.
- Understand the value of ‘natural supports’ in decision-making.
- Experience hope from being equal in mutual support, dignity and rights.

Differences in backgrounds and abilities of participants represent a learning opportunity rather than a challenge. A follow-up Handbook for trainers will make available methods of internal differentiation of learners, and group work.

The training will be set in an atmosphere of mutual respect, engagement and hope that will enable different ways of learning and understanding.

5.2 Three-day training and educational goals

The three day training is intended for a smaller group of around 12 participants focusing on people with disabilities and their supporters from families and support services. The educational goals are defined on a more practical level to enhance participant reflexivity regarding their own decision-making and the support in the decision-making of other people.

- Understand that all people make decisions, and use support in decision-making of some kind. People with disability have the right to legal capacity, and the right to receive an appropriate support in exercising this right.

³⁰ In the project IDEA 12, a larger group is a group of around 30 participants.

- Understand the meaning of decision-making for legal acts, and distinguish between “decision-making” and “legal acts”.
- Understand the difference between “substitute decision-making” and “supported decision-making”, and understand the meaning of supported decision-making in the lives of people with disabilities and its relations to other human rights covered by the Convention (e.g., independent living and community participation, or access to justice).
- Become familiar with, and embrace the principles of, supported decision-making.
- Understand and embrace the notion that a supporter has the support role and is not the decision-maker.³¹
- Be able to distinguish between my own “will and preferences” and the “will and preferences” of a supported person.
- Be aware of different kinds and intensity of support in decision-making.
- Be able to use basic tools of person-centred planning and thinking in providing support in decision-making.

In many countries, there will be a disconnect between the ‘paradigm shift’ away from substitute decision-making and the reality of living under legal systems that routinely require demonstrations of mental capacity and formally remove legal capacity. Trainers must be able to give practical tips on how to provide support in decision-making that is in line with the principles of Article 12, yet able to navigate the context of domestic laws in systems where there is more (or less) guardianship.

³¹ On the other hand, a supporter is supposed to put into the process his/her experience, knowledge, resources etc. The process is close to “shared decision-making” like “informed consent” practised in the field of medicine.

6 Training topics

The majority of the following topics are intended for both types of training (one-day and three-days). The topics intended for specific groups are marked. The level of detail will be specified in a Handbook for Trainers.

6.1 Implementation of Article 12 in the EU

Regarding the implementation of Article 12 of the CRPD, the Committee “*notes with deep concern that across the European Union, the full legal capacity of a large number of persons with disabilities is restricted*”.

“The Committee recommends that the European Union take appropriate measures to ensure that all persons with disabilities who have been deprived of their legal capacity can exercise all the rights enshrined in European Union treaties and legislation, such as access to justice, goods and services, including banking, employment and health care, as well as voting and consumer rights, in line with the Convention, as developed in the Committee’s General Comment No. 1 (2014) on equal recognition before the law.”

Exercising legal capacity can be conditioned by adjustment, also known as ‘reasonable accommodation’, of services such as banking or medical services. The Committee states that:

“[It] is concerned that Council directives 2000/43, 2004/113 and 2006/54 fail to explicitly prohibit discrimination on the grounds of disability and to provide reasonable accommodation to persons with disabilities in the areas of social protection, health care, (re)habilitation, education and the provision of goods and services, such as housing, transport and insurance”.

6.2 Implementation of Article 12 in the states of the IDEA 12 project partners

Several reports of the Committee suggested that implementation of Article 12 across European countries has not fully achieved requirements specified in the Convention. This means that participants in our training events operate within systems where varying degrees of substitute decision-making arrangements still exist. Trainers will inform their audience about the state of Article 12 implementation in their country based on concluding observations provided by the Committee.

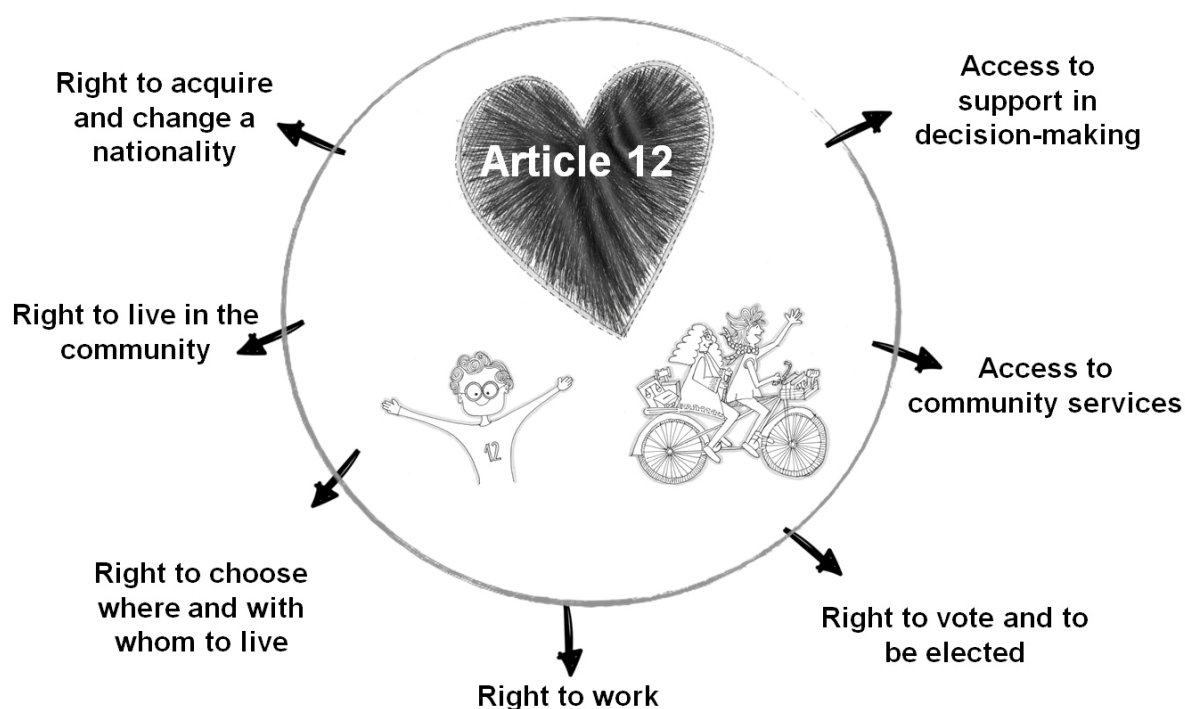
Each project partner provides a brief summary of Article 12 implementation in their country in Attachment No. 1. Information on the Convention ratification, concluding observations related to Article 5 and 12 and national legislation and practice.

6.3 What difference Article 12 makes in the lives of people with disability

Enjoying legal capacity (with needed support) in all aspects of life is a crucial condition for enjoyment of all other rights, such as the right to choose the place of living, to choose work, to vote and/or be elected among others.

Personal stories of people who have achieved restoration of their legal capacity, and how this changed their lives, provide excellent illustration.

Article 1 Full and equal enjoyment of all human rights and fundamental freedoms



Legal capacity (and support to exercise it) is crucial for many other domains. The following scheme shows that Article 12 is a pre-requisite for enjoying other human rights and fundamental freedoms and impacts various domains of life.

6.4 Paradigm shift in the concept of legal capacity

Art. 12 of the CRPD officially recognise the shift from the old model of legal capacity restriction to the new model of supported decision-making:

From substitute decision-making	To supported decision-making
Testing mental capacity for the purpose of deciding whether person's legal capacity has to be restricted or not	Assessing support needs for decision-making
Identifying the best interest (with the dominance of health & safety first)	Making all efforts to achieve the best interpretation of will & preference

Supported decision-making system is based on understanding legal capacity as a distinctive concept to the concept of mental capacity. It holds that the right to legal capacity cannot be derived from, and dependent on, a person's mental capacity.

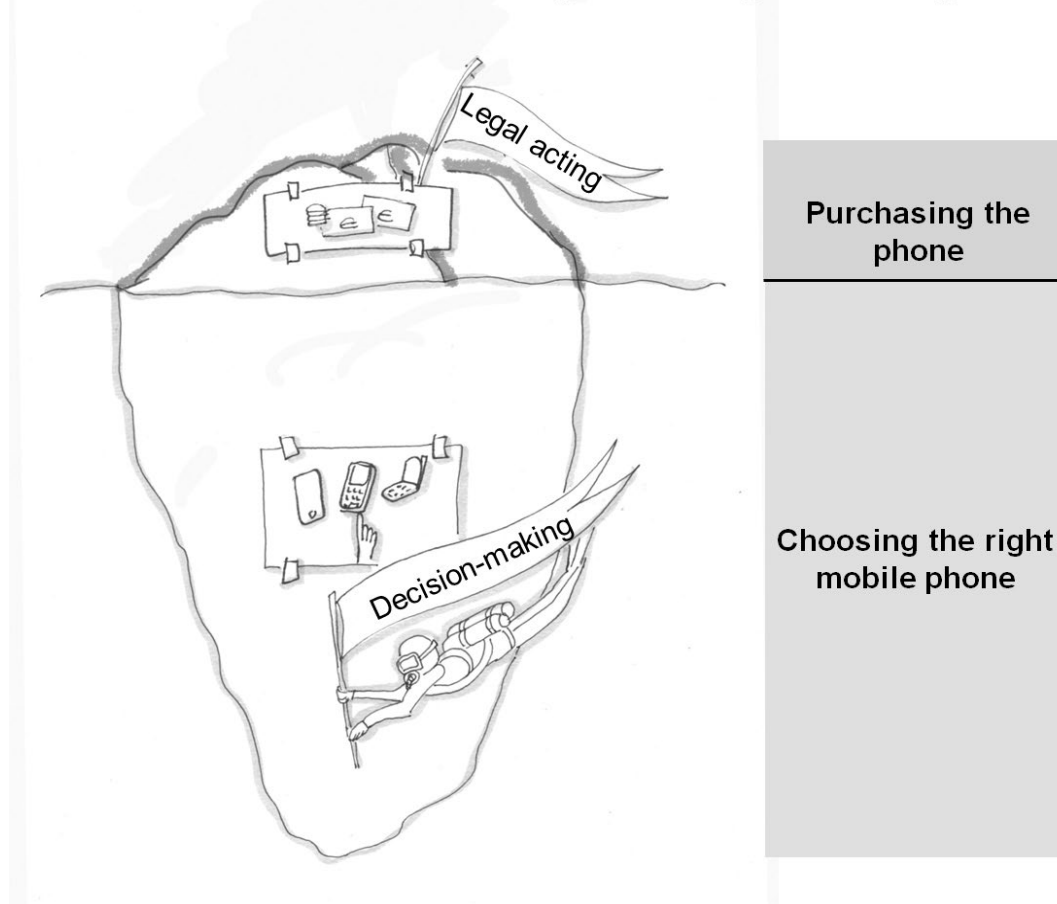
6.5 Support in decision-making in relation to legal capacity

A decision-making process may or may not result in a legal act. On the other hand, legal acts are always the result of a decision-making process. People very clearly perceive legal acts while the decision-making processes may remain undetected. Despite that, much of the decision-making can be quite robust and time-consuming, while legal acts such as purchasing a mobile phone can be very easy and quick.

To explain the relationship between decision-making and legal acts, we use the iceberg model where the decision-making process is represented as a mass of ice hidden under the water, and the legal act is the top of the iceberg.

As an example, we can use purchasing of a mobile phone, an action well known across cultures. When we want to buy a mobile phone we spend most of the time choosing it either in a discussion with friends or by exploring various options on the internet. Once we make a decision, purchasing the phone itself is quite a quick affair.

Decision-making and legal acting



6.6 Degree of support in decision-making

States have the responsibility to develop and provide different forms of support in decision-making as defined in the General Comment on Article 12. Each of these forms can vary in intensity of the support provided.

When providing support in decision-making it is important to think first about the level of support the decision-maker needs, or whether they need any support at all. We can distinguish between three levels of intensity of support in decision-making.

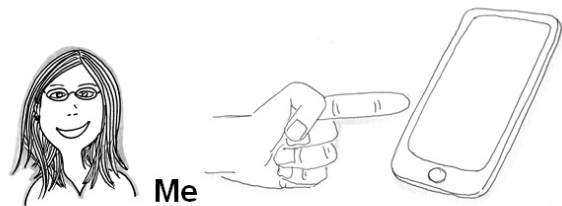
1. **A person makes their own decision** without any supplementary support from the supporters. They only need regular support in the form of a consultation with family members or friends.
2. **A person makes their own decision with support** from the supporters. This may involve support with identifying the decision, gathering information, explaining various alternatives, choosing from the alternatives, and reviewing the decision and its consequences. These

forms of support are more intensive compared to the consultation people regularly enact in everyday decision-making.³²

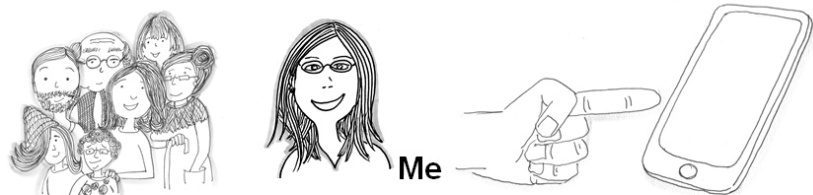
3. **A person's will and preferences are identified by supporters.** Supporters respect and are able to interpret person's will and preferences to third parties for the purpose of a legal act. Presumption of will is the leading principle for situation of people whose will and preferences is not known, now. The continual effort to understand a person's will and preferences and effort to establish communication with a person is expected.

Intensity of support in decision-making

Own decision
without any
supplementary
support



Own decision
with
supplementary
support



Decision based
on the best
understanding of
person's will and
preferences



Presumption of will. The person's will must be examined.

Two notes are important: 1) these three levels form a continuum in the intensity of support needed in decision-making. It is not necessary to distinguish between individual levels; 2) the same individuals may require different levels of support at different times and situations of decision-making.

When supporting a person with high levels of disability, without sufficient knowledge of their will and preferences we do not engage in supported decision-making but in a representation of the person.

³² We need distinguishing between level one and level two only for the purpose of identification of support needs. We have to be able to say that a state has to ensure some kind of support for a person.

We will follow socially-accepted values while striving to identify the person's will and preferences for further decisions.

6.7 Who can provide support in decision-making and exercising legal capacity

In the concept of supported decision-making, relationships are viewed as sources of support. Ideally, support is provided by a group of trusted others; primarily, non-paid, natural support from family and friends. In practice, very often the group consists of a range of trusted people from the social environment of the person and the professionals involved in their care and support. The person providing support can have a formal status – they can be formally approved or appointed by the court. The following chart shows the spectrum of possibilities.

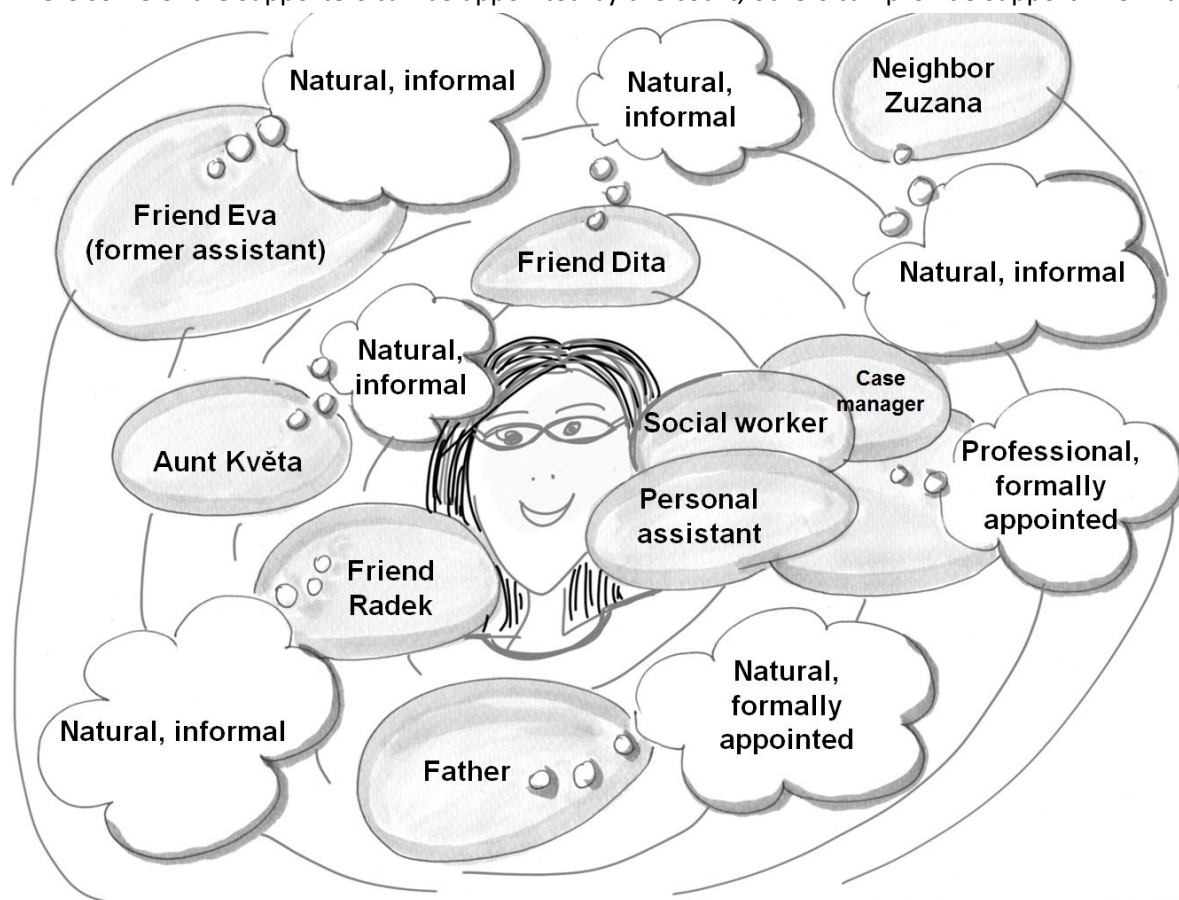
	Non-formal support (No formal act of recognition)	Formal support (Formally recognized by court, notary, civil contract, etc.)
Professional Support (Paid or non-paid professionals, including peer support)	<p>Personal assistant helps Jan to understand information given by the doctor about his health conditions before making a decision whether to consent to a surgical intervention.</p> <p>Philip, who is a former user of mental health services, provides support in decision-making regarding health care to a person in a psychiatric hospital.</p> <p>Peter who has lived experience with using support in decision-making helps his friend Marta with formulating her own opinion about her employment.</p>	<p>A professional supporter recognised by the court helps Eva to conclude a lease agreement.</p> <p>A member of an organisation of former users and survivors of mental health services has been appointed by the court to represent a person with mental health problems in court proceedings.</p> <p>A former user of mental health services who is a member of a multi-professional community assertive outreach team.</p>
Natural Supports (A range of people who are not paid)	<p>Thomas' mother helps him to manage his bank account.</p> <p>A neighbour helps Robert to understand benefits of different frying pans before he makes a decision which one to buy.</p>	<p>Vera's brother in the role of a supporter appointed by the court helps her to open a bank account and set up standing orders.</p>

Individuals can become expert by personal experience (e.g., people whose legal capacity has been questioned).

There is also mainstream support in decision-making which is available to all citizens. This support is provided by debt counsellors, tax advisors, experts who provide support in accessing social security payments, financial consultants, patient organisations, etc. We do not regard this type of support as part of support in decision-making under Article 12 because people who need support in decision-

making also usually require some kind of formal or non-formal support included the previous table support for using mainstream support.

In their life, people can rely on a dense net of support composed of natural and professional support where some of the supporters can be appointed by the court, others can provide support informally.



The crucial aspect of the support net is the relationship between the supporter and the supported person. The picture shows Milada's circle of support as an example.³³

6.8 Process of providing support in decision-making (3 day training only)

For a support person it may be beneficial to have a structured approach to support. Different people can use different elements of support. Below is the basic approach to support:

- 1) **Identifying the decision to be made:** Definition of the nature of the decision, the problem to be solved.
- 2) **Gathering relevant information:** Collection of information about needs, preferences, possibilities, sources of information (the internet, books, other people, other sources).
- 3) **Identifying alternatives:** Identification of possible paths of action or alternatives.

³³ Supported decision-making can build on concepts like Circles of support or Person centred planning – more in chapter 5.11.

- 4) **Considering alternatives:** Consideration of how different alternatives may solve the problem and what might be the consequences in each case.
- 5) **Choosing among alternatives:** After weighing all the evidence, the best alternative (or a combination of alternatives) is selected.
- 6) **Taking action:** For implementation of the decision (carrying out the chosen alternative) some action is needed to be taken – including legal acts.
- 7) **Reviewing the decision and its consequences:** In this final step, the results of the decision are reviewed and an evaluation is made of whether or not the need identified in Step 1 has been met. If the decision has not met the identified need, the whole process is repeated.

The nature of individual elements of support will vary depending on the person's needs. For example, their options can be explained to them in plain language, using graphics, or in sign language.

Two important notes: 1) Providing support in decision-making is a structured process based on theories of rational choice. Decision-making in real life is, however, mainly based on emotions, heuristic shortcuts and imitation. 2) Support should stem from deep understanding of the person rather than merely employ a technical, step-by-step approach.

6.9 Forms of support

Supports are “*resources and strategies* and can be provided by a parent, friend, teacher, psychologist, doctor, or by any appropriate person or agency”³⁴ such as a lawyer and a social worker. Support can have several forms:

- Personal support provided by supporters from the natural environment of the person (not paid, natural support) and professionals (paid support).
- Peer-support provided by people with similar experience (disability).
- Communication assistance: interpreters of the unique form of communication of a person.
- Different types of reasonable accommodation: plain language, alternative formats, easy-read materials, more time, and individualisation of service.
- Person-Centred Planning tools, including communication charts and future-planning meetings.
- Formal and informal representation of a person's will and preferences.

Support may be needed at any step of the decision-making process including (legal) acting on decisions and reviewing the decision. The intensity and form of support should reflect a person's individual need.

6.10 Key tools for decision-making support (3 day training only)

Some tools of Person-Centred Planning³⁵ which is a new approach to plan life and supports are useful in providing support in decision-making. The following tools are most valuable.

³⁴ http://aaid.org/docs/default-source/sis-docs/aaidfaqonid_template.pdf?sfvrsn=2

6.10.1 Circle of relationships and circle of support

A circle of relationships is the first step in creating a circle of support. It helps to make a clear picture about relationships of a person which can form the source of their support. The best support in decision-making is based on strong and trustful relationships.

One of the problems with professionalised models of supported decision-making is that “trust” is often ignored or taken for granted. It is often assumed that good intentions on the part of professionals will lead to building trusted relationships. It is important to make the professionals aware that they will not always gain the trust of people they work with, particularly if they are linked to the wider systems of coercion. It may be helpful for professionals to start discussing how to work within the limitations of their roles.

Another problem faced by many professionals is a lack of “continuity of care”. Rotation of professionals and task-oriented approaches may disrupt or break relationships of trust that need to be rebuilt each time.

6.10.2 Important to/for an individual decision-maker

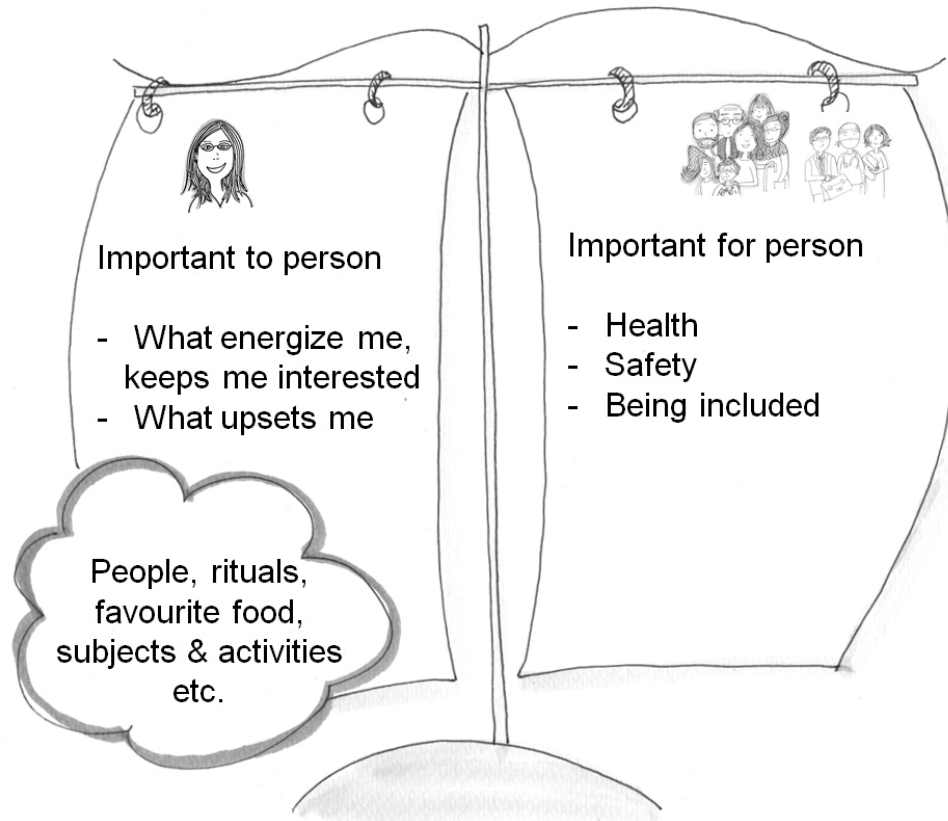
This tool is useful in situations when supporters are professionals or relatives with a strong responsibility for health and safety of a person. It allows them to distinguish their perspective from a person's will and preferences, and to keep the two perspectives separated. The ability of continuous reflection on the differences between the opinions of trusted persons and professionals on the one hand, and the will and preferences of supported persons on the other hand, must become embedded in social services and change the culture of service provision.

This sorting tool is crucial for supporters to accept that they are not supposed to perform substitute decision-making in their support role. This tool will help them to see and understand the principal difference between decisions made in the best interest of a person and those within a framework of supported decision-making.

To consider what is important ‘for’ a person from other people’s view first (see the column on the right) involves the risk of sliding into the “best interest” framework. Rather, it is preferable to start with the column on the left and to first learn and understand the will and preferences of the supported person based on what is important to them. This latter approach supports adhering to the “supported decision-making” framework.

³⁵ One of crucial characteristics of Person-Centred Planning is strengthening the voice of the person, and those who know the person best.

Sorting important to/for



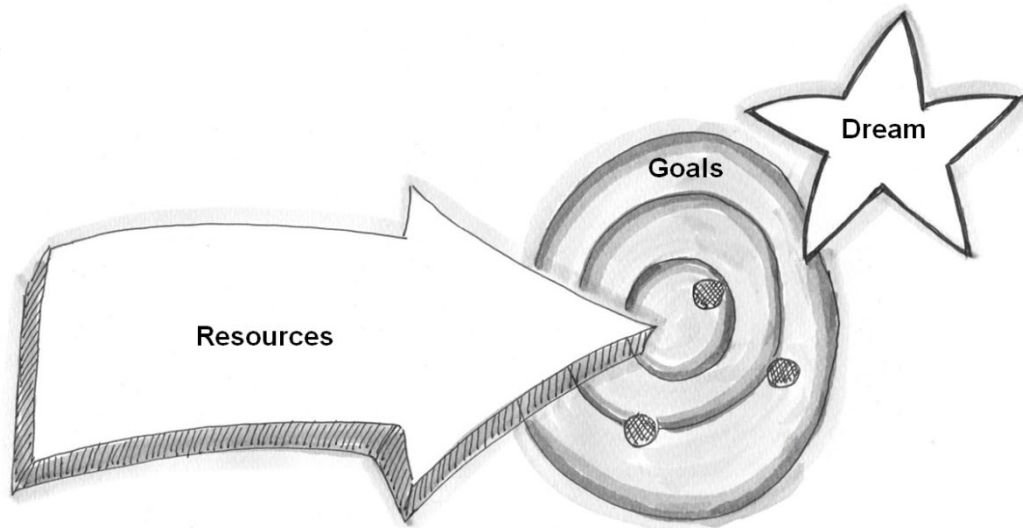
6.10.3 What's Working and What's not working

After identifying what is important to/for a person, we can use another sorting tool "What's Working and What's not working". It enables a person and their supporters to reflect on how things have been going in their lives, and what needs to be changed and solved. It could be used in the phase of identifying the decision to be made. It is important to keep the views of the supported person and the supporters separated in line with the outcomes of the "Sorting important to/for" tool. If necessary, it may be useful to separate out the views of the family/friends and professionals.

6.10.4 PATH

To provide support in everyday decisions, supporters may need to know the person's life direction³⁶. For this situation some of the methods of person-centred planning could be used effectively. PATH in particular seems to be effective to that end. PATH stand for **P**lanning **A**lternative **T**omorrow's with **H**ope and was developed in 1991 by Jack Pearpoint, John O'Brien a Marsha Forest (Falvey, Forest, Pearpoint, & Rosenberg, 2003: 31).

Basic scheme of PATH



PATH consists of 7 steps visualised in a specific format, and is used to facilitate a planning process. The basis of PATH is a template which reflects the process of discussion among people who are supposed to help a “focus person” to plan a practical journey leading towards a future that makes sense to them. The objective of PATH is to identify clear steps that will lead to a desirable change for the better. PATH starts with dreams of the “focus person” and continues with what the group considers should be the first steps towards achieving positive changes.

7 steps of PATH:

1. Dreams
2. Goals
3. Now
4. People to enrol
5. Ways to build strength
6. First steps
7. Next actions

³⁶ From the ethical point of view, supported person may also need to know supporters life direction. It allows a trustful relationship between supporter and supported person.

PATH is a great tool for setting out dreams, positive and possible goals of a person. It allows supporters to understand better the will and preferences of a supported person.

6.10.5 Communication charts

Communication charts are an effective way of capturing and informing others what people are telling us through their behaviour. This tool is especially helpful when people do not communicate with words or other formalised communication system (such as sign language and pictures), or when behaviours are a clearer method of communication than words.

Communication is a two-way process. That is why we need two types of charts: 1) How we understand what the person is telling us and 2) How we will communicate with the person what we would like them to do.

1. Chart of how the person communicates

The chart of how the person communicates can have two forms for two different situations. First, when we do not know what a specific behaviour means, we can try to explore the meaning in specific circumstances. The second situation is when the meaning is known only to some and we need to capture this knowledge for the use of everyone providing support. The chart then effectively serves like a dictionary.

Situation, circumstances:	Person is doing:	Person experiences and tells us:	We have to do:

2. How we tell the person with disability what we would like to do

This chart helps all support persons know what to say and what to do to make a person understand them.

We would like to say:	We do:	We say to the person:

Communication charts help us to understand a person. Understanding is the basic condition for providing support in decision-making.

6.10.6 Matching supporter

For specific areas of providing support, we also need specific knowledge and skills. In the case of a paid professional, a good match between the needs of a supported person and a supporter may be very important. We need to think about four aspects of the supporter personality:

1. Skills needed for providing support
2. Support needed and wanted – which specific areas of decisions
3. Personal characteristics the supporter needs to have

4. Shared common interests of the supporter and the supported person

6.11 Four important elements of supported decision-making

For implementation of Article 12 and the principles of supported decision-making, the following elements and corresponding provisions of the Convention are crucial (Bach, 2014: 4-5):

1. People with disabilities have the right to **enjoy legal capacity** on an equal basis with others in all aspects of life. In practice it means that people with disabilities make decisions and their decisions are respected. [Article 12 (2) CRPD]
2. States have an **obligation to provide supports** (where needed) to help people in exercising legal capacity. [Article 12(3) CRPD]
3. States have an **obligation to provide safeguards** to prevent abuse and ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and **protect from exploitation, violence and abuse**. [Article 12(4) & Article 16 CRPD]
4. States shall take all appropriate steps to ensure that **reasonable accommodation** – adjustment that enables persons with disability to exercise human rights on an equal basis with others – is provided. [Article 5(3) CRPD]

Awareness of these key points is important in systemic thinking about the implementation of Article 12.

6.12 Reasonable accommodation

The notion of reasonable accommodation is defined in Article 2 of the CRPD as *“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”*. To exercise legal capacity, reasonable accommodation may include³⁷:

- More time, plain language, easy-read materials
- Inclusion of supporters in the decision-making process and legal action
- Duty to accept levels of independence in decision-making and legal actions. Those may vary in different situations (e.g. managing financial matters independently without a support person; making independent decisions regarding some health issues)

³⁷ Adapted types of accommodation according to M. Bach (Bach, 2014: 9)

7 Acknowledgment

This document was prepared with valuable feedback from the following persons and organisations. We would like to thank all of them:

1. Inclusion Europe

Rue d'Arlon 55 – B-1040 | Brussels – Belgium
<http://inclusion-europe.eu/>

2. European disability forum

Square de Meeus 35 | 1000 Brussels | Belgium
<http://www.edf-feph.org/>

3. League of Human Rights

Burešova 6 | 602 00 Brno – Czech Republic
<http://llp.cz/>

4. European Network of (Ex-)Users and Survivors of Psychiatry (ENUSP)

Vesterbrogade 103, 1.sal | 1620 Copenhagen V – Denmark
www.enusp.org

5. Inclusion Czech Republic

Karlínské square 12 | 186 00 Prague 8 – Czech Republic
www.spmprcz.cz

6. Yotam Tolub

Bischut | 3 Kanfei Nesharim st. | 9546406 Jerusalem – Israel
<http://bizchut.org.il>

7. National Board of People with Disability

Partyzánská 1/7 | Prague 7 – Czech Republic
<http://www.nrzp.cz/>

8. Dr. Piers Gooding

Melbourne Social Equity Institute, Melbourne Law School, University of Melbourne
Victoria 3010 | Melbourne – Australia

9. Mental Health Europe

Mundo B- Rue d'Edimbourg 26 | 1050 - Bruxelles
<http://www.mhe-sme.org/about-mhe/meet-the-staff/>

10. Dr Lucy Series, Research Associate

Cardiff School of Law and Politics - UK
Cardiff University / Prifysgol Caerdydd

11. The Association for Help to People With Intellectual Disabilities in The Slovak Republic

Štúrova 6 | 811 02 Bratislava – Slovakia

- <http://www.zmpvrs.sk/>

12. Office of the Commissioner for Persons with Disability

Račianska 153 | 831 54 Bratislava 35 – Slovakia

- www.komisarprezdravotnepostihnutych.sk

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9 Attachment No 1: The status of implementation of SDM and reasonable accommodation (reports provided by project partners)

9.1 The Czech Republic

9.1.1 Ratification of the Convention

In the Czech Republic the Convention was ratified in October 2009. It entered into force when it was published in the Collection of International Treaties in February 2010. The ratification of the Optional protocol is being protracted.

9.1.2 Concluding observation on the initial report

The UN Committee on the Rights of Persons with Disabilities considered the initial report of the Czech Republic (CRPD/C/CZE/1) at its 180th and 181st meetings (CRPD/C/SR.180 and 181), held on 31st March and 1st April 2015 respectively, and adopted the following concluding observations at its 192nd meeting held on 10 April 2015.

Article 5:

“(9) The Committee notes with concern that under the Anti-discrimination Act the duty to provide reasonable accommodation is limited to employment and related labour relations. ... (12) The Committee calls upon the State party to take all necessary measures, including training of the judiciary, strengthening of independent human rights bodies and capacity- building of persons with disabilities and their organisations, to foster the use of available legal remedies by persons with disabilities facing discrimination and inequality.”

Article 12:

“(22) The Committee notes with concern that the new Civil Code still prescribes for the possibility of limiting one’s legal capacity and putting a person with disability under partial guardianship.

“(23) The Committee calls upon the State party to amend its Civil Code and fully harmonise its provisions with article 12 of the Convention, as elaborated in the Committee’s General Comment No. 1 and recognise the full legal capacity of all persons with all types of disability, and to improve access to supported decision-making and implement the provision of the Civil Code.”

9.1.3 National legislation and practice

In the Czech Republic a new Civil Code³⁸ was adopted (published) in 2012 and came into force in 2014. The civil law reform was initiated in the 1990s and the final version of the law proposal was opened for public comments in 2008. At the time, sections of the proposed Civil Code related to legal capacity did not reflect the progress in disability field and failed to take the Convention into account. During the consultation, several NGOs and organisations of people with disabilities provided extensive comments and placed THE CONVENTION on the agenda. The present wording is a

³⁸ Act No. 89/2012 Coll., Civil Code; English version: <http://obcanskyzakonik.justice.cz/images/pdf/Civil-Code.pdf>

compromise achieved within a limited negotiation time between the initial text and the requirements of the Convention. It is perceived by local disability rights organisations as a significant step ahead.

The new Civil Code introduced several new tools that can be used as alternatives to limiting legal capacity. The most important are: Advance directive, Agreement on support in decision-making, Representation by a household member, and Guardianship without restriction of legal capacity. The Trust fund is another measure which may currently be used to protect property and prevent the use of restriction of legal capacity. Despite the benefits introduced by these tools, none of them fully meets the requirements of the Convention. The most CRPD compliant are Agreement on support in decision-making and Guardianship without restriction of legal capacity. They allow for the will of a person with disability to be fully respected. A related ongoing issue is that the new law does not provide for sufficient safeguards.

The new Civil Code still recognises partial restriction of legal capacity. However, it is meant to serve as a last resort intervention. It can be used only if (1) the individual would be otherwise subject to a risk of substantial harm and (2) any of the less restricting measures was not sufficient to prevent the risk. In practice, the dominant way of thinking is still in terms of previous legislation. There is lack of understanding how to use the new tools in judicial and social system and in the society. The result is that courts still opt for extensive restriction of legal capacity impacting on most of the areas of life as prevailing practice.

9.2 United Kingdom

9.2.1 Ratification of the Convention

CRPD was ratified in 2009.

9.2.2 Concluding observation on the initial report

The UN Committee on the Rights of Persons with Disabilities published an initial report in 2013, there are, however, not yet concluding observations.

9.2.3 National legislation and practice

In Scotland, mental capacity is governed primarily by the Adults with Incapacity (Scotland) Act 2000; in England and Wales it is governed by the Mental Capacity Act 2005. Northern Ireland has recently passed the Mental Capacity Act (Northern Ireland) 2016 SI 2016/18. Each of these laws limits legal capacity in connection to a functional test of mental capacity³⁹. This practice is coupled with a discriminatory ‘diagnostic criterion’ which means that a person who fails the functional test is treated as lacking legal capacity only if that is caused by *“in impairment or disturbance in the functioning of the mind or brain”* (in England and Wales)⁴⁰ or a *“mental disorder”* (in Scotland)⁴¹. In Northern Ireland, in an effort to comply with the Convention, mental incapacity must still be caused by an *“impairment or disturbance in the functioning of the mind or brain”*, but additionally specifies that *“it does not matter whether the impairment or disturbance is caused by a disorder or disability or*

³⁹ s3 MCA; s1 AWIA; s4 MC(NI)A 2015

⁴⁰ S2(1) MCA

⁴¹ s1 AWIA

otherwise than by a disorder or disability".⁴² It remains to be seen whether this will reduce any indirect discriminatory effect on persons with disabilities⁴³.

Throughout the UK, capacity legislation is still wedded to a "best interests" paradigm. In England and Wales, the law requires decisions to be made in the "*best interests*" of persons lacking legal capacity, and a person's wishes, feelings, values and beliefs are to be "*considered*". These are, however, given little special weight in the best interests decisions⁴⁴. In Northern Ireland, "*special regard must be made to the person's wishes, feelings, values and beliefs in the best interests*" decisions. Similarly, there is no presumption or specific weight attached to these⁴⁵. In Scotland, "*interventions' are permitted only where the intervention will benefit the adult and [...] such benefit cannot reasonably be achieved without the intervention*".⁴⁶ This test was introduced to give greater weight to the person's wishes and feelings compared to the "best interests" test. Analysis of case law indicates that in practice the test still functions, however, like a "best interests" test⁴⁷.

Provisions for support for the exercise of legal capacity in each jurisdiction are limited to mechanisms intended to support decision-making and to enable a person a greater probability of passing a functional test of mental capacity. These are not required to be based on the person's "will and preferences". In each jurisdiction it is unclear **who** is required to support a person in decision-making; there is also no mechanism enabling a person to nominate a trusted support person.

In England and Wales, "[a] person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success, and [a] person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or any other means)".⁴⁸

In Scotland, there is no reference to supporting decision-making, simply a statement that the adult should be encouraged "*to exercise whatever skills he has concerning his property, financial affairs or personal welfare, as the case may be, and to develop new such skills*".⁴⁹

In Northern Ireland there are more detailed support provisions, which include "*ensuring that persons whose involvement is likely to help the person to make a decision are involved in helping and*

⁴² s3 MC(NI)A 2015

⁴³ Martin, W., Michalowski, S., Stavert, J., Ward, A., Ruck Keene, A., Caughey, C., Hempsey, A. and McGregor, R. (2016) *The Essex Autonomy Project Three Jurisdictions Report: Towards Compliance with CRPD Art. 12 in Capacity/Incapacity Legislation across the UK*, University of Essex

⁴⁴ s4(6) MCA

⁴⁵ s7 MC(NI)A 2015

⁴⁶ s1 AWIA 2000

⁴⁷ Ruck Keene, A. and Ward, A. (2016) 'With and without 'best interests': The Mental Capacity Act 2005, the Adults with Incapacity (Scotland) Act 2000 and constructing decisions', *International Journal of Mental Health and Capacity Law*, 1(1)

⁴⁸ s1(3) MCA and s3(2) MCA

⁴⁹ s1(5) AWIA

supporting the person". Again, however, support is not based on the person's will and preferences and it is support for passing the functional test rather than support for exercising legal capacity⁵⁰.

The Law Commission in England and Wales has suggested the introduction of a scheme permitting nominated support persons. It has yet to be seen whether this will be adopted⁵¹. Each jurisdiction provides frameworks for advance planning, but these are based on requirements that the adult has mental capacity, which is likely to be especially problematic for adults with learning disabilities where prejudicial assumptions may mean that decision makers may not be "satisfied" that the adult concerned validly made the advance decision.

To sum up, there is a significant potential in each jurisdiction for discriminatory application of restrictions on legal capacity for adults with mental disabilities, and substitute decisions based on a 'best interests' paradigm that does not accord sufficient respect for people's rights, will and preferences. Support mechanisms, where available, are piecemeal and not based on supporting the exercise of legal capacity in accordance with the will and preferences of the person. There is insufficient recognition of the importance of trusting and chosen relationships of support. Awareness of the requirements of Article 12 of the CRPD is low among policymakers, the judiciary and even many disabled people's organisations. There is a need for a program of education for government, the judiciary and civil society organisations.

9.3 Latvia

9.3.1 Ratification of the Convention

Latvia ratified the Convention on 1 March 2010. It entered into force on 31 March 2010.

9.3.2 Concluding observation on the initial report

Latvia a review by the UN Committee on the Rights of Persons with Disabilities was planned for in Spring 2017.

9.3.3 National legislation and practice

Until January 1, 2012, the Latvian law provided that any individual who was determined to lack (partially or fully) their mental capacity could have their legal capacity fully restricted. A judgement of the Constitutional Court of Latvia (case No 2010-38-01)⁵² meant that the provision had to be amended. A new regulation of legal capacity entered into force in 2013. It abolished Plenary guardianship and introduced partial legal capacity restrictions, where only material rights may be restricted. The court may no longer restrict an individual's personal non-material rights and their right to represent themselves before the authorities and in court. Among other non-material rights that cannot be restricted under any conditions are the right to vote, right to marry, right to make decisions on children, and right to make decisions related to medical treatment.

⁵⁰ s5 MC(NI)A

⁵¹ Law Commission (2015) *Mental capacity and deprivation of liberty: A consultation paper*, (Consultation Paper 222) London

⁵² 27 December 2010 Judgment of the Constitutional Court no.2010-38-01, para. 10 - http://www.satv.tiesa.gov.lv/wp-content/uploads/2010/04/2010-38-01_Spriedums_ENG.pdf

Considering issues of legal capacity where decisions about non-material issues must be made, the amended Civil law and Civil Procedure law hold that:

1. Any person, at any point in time, may issue an advanced directive, in which a specific individual or group of individuals are provided the authority to make decisions concerning important life events on behalf of the issuer if it were the case that the issuer at any future point in time be unable to act or unable to express their will due to any health problem, including a mental health problem.

2. In case of imposing restrictions on legal capacity, individuals can have a temporary guardian appointed for a period of time no longer than two years. This solution can be applied if the individual is in a state of health that prevents them from communicating and expressing their will, and it is necessary to ensure the protection of their interests and rights. This solution is possible if:

- a) it is urgently needed to protect the individual's interests;
- b) the individual's health problems are transient;
- c) the individual cannot do harm to him/herself through his/her actual conduct.

3. An individual may have his/her legal capacity partially restricted, and be appointed a guardian. Person's legal capacity may only be restricted in certain areas, for instance, in issues of finance and regarding the right to manage property. Full restriction of legal capacity is no longer permitted.

a) When appointing a guardian, the court's first obligation is to define the areas in which the guardian and person with partially restricted capacity will act together. Only after defining the areas requiring joint action can the court then determine in which areas the guardian will have the right to act independently.

b) The individuals themselves have the right to ask for a re-evaluation of their legal capacity at any time.

c) The law requires restrictions of legal capacity to be periodically re-evaluated and it is scheduled for every seven years.

The application for temporary guardianship and restriction of legal capacity can only be submitted by a close relative and the prosecutor's office. The previous regulation allowed anyone to apply.

The new regulation is still not fully compliant with Article 12 of the CRPD. Alternatives to the restriction of legal capacity, such as supported decision-making mechanisms, were not included in the law.

NGO-RC ZELDA since February 2015 has been providing direct support in decision-making to 28 persons with learning disability and/or psychosocial disability on a regular basis. RC ZELDA also provides regular consultative support to natural supporters. Moreover, the government of Latvia plans to implement bigger scale pilot project of supported decision-making in period of 2017 till 2020. In the meantime RC ZELDA continues to advocate for necessary changes in law and to provide daily support in decision-making to persons who have developed trustful relationships with RC ZELDA staff.

9.4 Lithuania

9.4.1 Ratification of the Convention

Lithuania ratified the Convention and its Optional Protocol on 27 May 2010 by passing the Law on ratification of the Convention on the rights of persons with disabilities. It came into force on 18 Aug 2010.

9.4.2 Concluding observation on the initial report

The UN Committee on the Rights of Persons with Disabilities reviewed the initial State report on the implementation of the Convention on its 15th session in April 2016 and adopted several Concluding Observations to the Republic of Lithuania on 21 April, 2016.

Regarding article 5

“The Committee is deeply concerned that the State party does not consistently apply the concept of reasonable accommodation in relation to the principle of non-discrimination.”

Regarding article 12

“The Committee is deeply concerned at the legal provisions permitting the denial or restriction of the legal capacity of persons with disabilities contrary to article 12 of the Convention, which thereby limit rights of persons with disabilities to give their free and informed consent for treatment, to marry, to found a family and to adopt and raise children.

“With reference to its General Comment No. 1 (2014) on equal recognition before the law, the Committee recommends that the State party repeal laws, policies and practices permitting guardianship and trusteeship for adults with disabilities and replace regimes of substituted decision-making with regimes of supported decision-making.”

9.4.3 National legislation and practice

In Lithuania, legal institutes of legal incapacity, guardianship and partial guardianship are regulated by the Civil code of the Republic of Lithuania (2000) and the Code of Civil Procedure of the Republic of Lithuania (2002).

Up until then, legal norms on legal incapacity were provided by the 1964 Civil Code which for more than 50 years discriminated against persons with psychosocial and intellectual disabilities. A medical diagnosis on its own could serve as the basis for limiting all rights of a person. The majority of persons declared as legally incapable were then placed in residential institutions. The institutions were also appointed legal guardians of the persons. As a result, the majority of people with disability were denied daily decisions, realisation of basic rights, and lived segregated from the society.

The background for legal reform was formed especially by ratification of the UN Convention on the Rights of Persons with Disabilities (2010) and commitments to implement the provisions of Article 12 of the CRPD and ECHR decision, 2012 D. D. vs Lithuania indicating that legal regulations on legal incapacity violates Article 5 paragraphs 1, 4 d. and Article 6 paragraph 1 of European Convention on Human Rights.

After the long process of drafting of the Law on amendments to the Civil Code and Code of Civil procedure initiated by the Ministry of Justice, Lithuanian Parliament on 26 March, 2015 adopted amendments of the Civil Code, which came into force on 1 January 2016.

Amendments to the Civil Code introduce new support measures as an alternative to status of incapacity. These are: (1) Assistance in decision-making agreements to be signed by the persons in need of support in decision-making, including, but not limited to mental disabilities. It is subject to notary's certification and registration in the Register. (2) The Advanced Directive defines how matters should be dealt regarding implementation of person's property and non-property rights in case his/her capacity would be restricted or s/he would be declared incapable in the future. It is subject to notary's certification and registration in the Register. It comes into effect by a court decision, declaring the person incapable or restricting his/her capacity and become binding for all persons and institutions.

In 2016, the "*Registry of persons declared as incapable or partially capable*" listed 6998 persons declared as incapable. Since the reform, 69 of them have been declared as incapable in all the areas and 25 as incapable in specific areas of life. The rest of 6904 people stayed declared as incapable with no areas indicated from period before January 1, 2016. There are only four advanced directives registered and three contracts of supported decision-making.

The amended law still allows a person have their legal capacity restricted in certain areas and entitles a third person (guardian) to decide on the person's "best interests".

A 2015 Order of the Minister of Social Security introduced a **new role for municipal social workers**. Social workers were entrusted with the assessment of *persons' capacities to take daily decisions independently* or with support in cases when planning and starting application for the court to restrict person's legal capacity in one or another area of life. Social workers thus provide assessment required to be done by the court in legal capacity cases. Moreover this legal requirement raises a new paradoxical issue for social worker. The assessment of the mental capacities of a person with intellectual and psychosocial disabilities inevitably leads a social worker to provide clinical evaluation. The social worker becomes an instrument for declaring a person incapable or being restricted in her/his legal capacity instead of providing assessment of support needs and supporting the person in the decision-making.

There is limited development of supported decision-making models and trained supporters or guardians to enable persons with disabilities to make decisions. It makes it impossible to use the new tools of the Civil Code.

9.5 Slovakia

9.5.1 Ratification of the Convention

The Convention in the Slovak Republic was signed on 26 September 2007 and ratified on 26 May 2010. It became effective on 25 June 2010 and is now part of Slovak law (Notification of the Ministry of Foreign Affairs of the Slovak Republic No. 317/2010 Coll.).

9.5.2 Concluding observation on the initial report

The UN Committee considered the initial report of Slovakia (CRPD/C/SVK/1) at its 242nd and 243rd meetings (see CRPD/C/SVK/SR.242 and 243), held on 4 and 5 April 2016 respectively. It adopted the concluding observations at its 256th meeting, held on 13 April 2016.

Regarding article 5:

“The Committee is concerned that reasonable accommodation has been misinterpreted as a temporary special measure and that there is a lack of an explicit definition of reasonable accommodation in legislation. The Committee is concerned that the denial of reasonable accommodation as disability-based discrimination is not recognised in law.”

Regarding article 12:

“The Committee is concerned that, despite recent legal and procedural reforms, all persons with disabilities are not given equal recognition before the law and are denied the right to vote, the right to marry and found a family, enjoy property and to retain fertility.

“The Committee recommends that the State party repeal section 10 (1) of the Civil Code, which provides for deprivation of legal capacity, and section 10 (2) of the Civil Code, which provides for restriction of legal capacity, and to introduce supported decision-making which respects the autonomy, will and preferences of the individual.”

9.5.3 National legislation and practice

On 1st September 2015 the law established the institution of public protection of the rights of persons with disability. The commissary and her/his team are involved in the process of the protection of the rights of persons with disability, providing support to persons with disability according the Convention.

Slovak law became partially compliant with Article 12 of the CRPD on 1 July 2016 when the Civil Procedural Code for Non-dispute Proceedings became effective. Slovak courts may no longer pass a decision on restricting the legal capacity of an individual in full. The most serious breach of Article 12 of the CRPD in the Slovak law is now (partial) restriction of legal capacity. The legislator highlighted that any declaration of legal incapacity after 2010 is in breach of the Convention in an explanatory report to Section 231 of the Act No. 161/2015 Coll. Civil Procedural Code for Non-dispute Proceedings, which was adopted on 21 May 2015.

In general, as the new legislation promotes the right to legal capacity, more people are claiming to restore or keep their legal capacity. However, there are still significant gaps in the current system of providing support in decision-making.

Notwithstanding the amendment of procedural rules, which no longer allow the declaration of legal incapacity, formally this option still remains even if inapplicable. That is because Section 10(1) of the 1964 Civil Code reads that, *“if, due to mental illness that is not merely temporary, an individual is not capable to perform legal acts at all, the court will detain his legal capacity [in full]”*. Furthermore, Section 10(2) stipulates that, *“if, due to mental illness that is not merely temporary or due to excessive use of alcoholic drinks, drugs or poisons, an individual is capable of performing only certain legal acts, the court shall restrict his legal capacity and stipulates the scope of restriction in the*

decision". Finally, Section 10(3) reads that, "the court will change or abolish the restriction or declaration of incapacity, if there has been change to the reasons for such decision or if the reasons have ceased to exist".

Within the new law system restriction of legal capacity is meant to be the last resort. Courts have to define the imminent harm that, to be avoided, requires restrictions of legal capacity in specific areas. Court decisions must specify who or what is threatened by the full capacity of the individual.

Section 29 of the Civil Code may be an option through which a person with disability may be provided help with legal acts without the need to restrict their legal capacity. Section 29 of the Civil Code reads that, *"The court may appoint a guardian to a person the whereabouts of which are not known if it is necessary for protection of their interests or if there is public interest in such action. Under the same conditions the court may appoint a guardian if it is necessary from other serious reason."*

9.6 Spain

9.6.1 Ratification of the Convention

The Convention in Spain was ratified on 3 December 2007.

9.6.2 Concluding observation on the initial report

The UN Committee considered the initial report on Spain (CRPD/C/ESP/CO/1) at its 56th and 57th meetings (CRPD/C/6/SR.3 y SR.4), held on 21 September 2011 and adopted the following concluding observations at its 62nd meeting, held on 23 September 2011.

Regarding article 5

"(19) The Committee welcomes the regulatory amendments introduced under Act 26/2011 that would abolish the need to have a disability certificate to bring a discrimination claim before a judicial body. However it regrets the lack of information on cases of discrimination, and it is concerned that persons with disabilities will still be marginalised. The Committee is further concerned by the lack of information on reasonable accommodation. It is also concerned that, in practice, disability affects parents' guardianship or custody of their children and that legal protection against discrimination on the grounds of disability is not enforceable in cases of discrimination due to perceived disability or association with a person with a disability.

"(20) The Committee urges the State party to expand the protection of discrimination on the grounds of disability to explicitly cover multiple disability, perceived disability and association with a person with a disability, and to ensure the protection from denial of reasonable accommodation, as a form of discrimination, regardless of the level of disability. Moreover, guidance, awareness-raising and training should be given to ensure a better comprehension by all stakeholders, including persons with disabilities, of the concept of reasonable accommodation and prevention of discrimination."

Regarding article 12

33. *The Committee notes that Act 26/2011 allows a period of one year following its entry into force for the presentation of a bill to govern the scope and interpretation of article 12 of the Convention. The Committee is further concerned that no measures have been taken to replace substitute decision-making by supported decision-making in the exercise of legal capacity.*

34. *The Committee recommends that the State party review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences. It further recommends that training be provided on this issue for all relevant public officials and other stakeholders.*

9.6.3 National legislation and practice

The Spanish Civil Code allows substitute decision-making based on a discriminatory approach to disability⁵³. A judge may assess a person's ability to manage their affairs and establish total or partial guardianship (which implies substitute decision-making) or curatorship (which implies support to decision-making of a kind). Curators only support persons in specific legal acts. The curator cannot represent the person, they need to take decisions and act together. If the person acts without the acquaintance of their curator, the legal act may be declared void in cases of detrimental effects on the person.

Catalonian Civil Code in Book two, Chapter Six⁵⁴ allows the use of “support” “(asistencia)” to assist a person in managing their lives (article 226 et seq.). However, the support can only be used by people with a non-disabling capacity decrease, i.e. when the disability does not limit or prevent the capacity of self-management.

In Spain there are no accessible data about the number of people under guardianship and curatorship. However, there are indications that numbers of people with disability whose legal capacity has been restricted have not decreased since the ratification of the Convention. In fact, at a recent seminar, a forensic doctor said that in the court of Zaragoza alone, incapacitation cases increased by 60% between 2010 and 2015. Similarly, a recent report⁵⁵ of the Spanish Association of Guardianship Foundations (AEFT) concluded that between 2010 and 2016 the number of their users grew by 6% every year. The report also claimed that 82% of their users were under guardianship and 12% under curatorship.

Recently, the Spanish General Codification Commission has prepared a preliminary draft bill to revise the Civil Code and make it compliant with the Convention. At the same time, the Spanish Supreme Court, High Courts, and the Office of the Attorney General have made some advances in the interpretation of the legislation taking the Convention into account.

⁵³ Article 200. Incapacitation causes are persistent diseases or deficiencies of a physical or psychic nature that prevent the person from governing himself.

⁵⁴ <https://www.boe.es/buscar/act.php?id=BOE-A-2010-13312>

⁵⁵ http://fundacionestutelares.org/wp-content/uploads/2016/12/EstudioTutela_AEFT.pdf