

## Position Paper - Key Elements of a System for Supported Decision-Making

# **Key Elements of a System for Supported Decision-Making**

## **Position Paper of Inclusion International**

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**The UN Convention on the Rights of Persons with Disabilities demands in its Article 12 equal recognition before the law for all persons with disabilities. This Position Paper explores which key elements are necessary to implement this principle in the legal systems of all countries that have ratified the Convention. Starting from the discussion of some basic notions regarding legal capacity, the Position Paper identifies eight elements that should be considered in the implementation of this article to make the UN Convention a tool that promotes the rights of persons with intellectual disabilities.**

The United Nations adopted in December 2006 the Convention on the Rights of Persons with Disabilities. One of the core messages of the Convention is that persons with disabilities should not be seen as objects but as human subjects deserving equal respect and treatment. The Convention is an internationally agreed binding legal document, which provides directions for the international community. It is a tool, a driver for domestic changes.

The Convention has introduced a paradigm shift in international and national law with the concept of “supported decision-making”. Supported decision-making means that there is no transfer of rights to other persons: disabled people fully enjoy all their rights. Therefore supported decision-making is intended to replace guardianship systems. While existing guardianship legislation proceeds with the partial or total legal incapacitation of disabled people, Art. 12 of the UN Convention on the Rights of People with Disabilities clearly declares that disabled people shall enjoy “legal capacity on an equal basis with others”.

Legal capacity should be understood as the capacity to have rights and the capacity to act. The Convention also stipulates that people with disabilities shall receive “the support they may require” in exercising their rights. Traditional guardianship laws declare the individual legally incompetent in all or several areas and appoint a legal guardian who takes decisions as a substitute for the individual. With traditional guardianship laws, people with disabilities are partially or fully deprived of their rights. This system has led very often to the depersonalization of the disabled individual who no longer is deemed to be a full and equal citizen in society. Therefore, the Convention introduces a fundamental shift of thinking from substitute decision-making to supported decision-making of disabled people.

It is the purpose of this paper to identify some of the necessary conditions for the transposition of this paradigm shift into national laws. While the concrete transposition will be rather different for countries which become States Parties to the UN Convention, depending on legal structures and traditions, this Position Paper sets out to consider crucial elements without which national laws may fall short of the intentions manifested in Article 12 (of the UN Convention). For supported decision-making to become a reality, States Parties are not only required to consider reforms of their national guardianship legislation, but it is furthermore important to implement a number of non-legal structures and measures in addition to the necessary legal instruments.

Since the issues related to legal capacity are linked to the basic structure of our societies, it is also important to ponder some of the underlying philosophical questions in order to develop an adequate approach to the question at hand.

## Background

It is important for the discussion of legal capacity to understand the interdependence of members of societies:

- There is possibly no individual in any society who is truly independent of the influence of others. Social structures and hierarchies, the need for positive attention, economic necessities, etc. create dependencies for all non-disabled and disabled citizens that must be taken into account.
- Equally, many citizens feel the need to receive support for decisions on complex issues to other people if they believe that they themselves do not have the capacity to decide. Examples are financial consultants, medical doctors, architects and all the other professions that provide expertise to all citizens.
- Many decisions are also not taken in the best interest of the person who takes the decision. Often they are determined by factors that are not logically based: commercial advertisements, the wish for social status, the preference for nice fast cars, etc.

In addition, the justification of any intervention affecting basic rights of the individual, especially the personal freedom and the physical integrity of a person, generally requires the informed consent of the person concerned.

Thus, when discussing the issue of supported decision-making, one needs to understand that the determining factors are always the perceived level of dependence, the level of capacity and the degree of deciding against one's best interest. The difficulty is increased by the fact that in this context, it is most often other people who judge these degrees for another individual.

## The issue of legal capacity

The need for specific rules and legislation regarding individuals who are deemed to be incapable to take a specific decision stems from the need for their participation in legal decision-making procedures as well as for legal protection, both for the individual and also for the individual's counterparts in society.

- People interacting with persons who they perceive to have reduced capacity to decide have the interest to ensure that their contracts and agreements are legally valid. For example in the areas of medical interventions or of financial transactions, medical doctors or banks must be protected against claims that they may have exploited the incapacity of a person to take a specific decision.
- Persons perceived to have reduced capacity to decide have the interest to participate independently in the life of society. At the same time, they have to be protected from abuse and exploitation and possible negative consequences of decisions that they possibly do not fully understand.

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1. It is interesting to consider in this context protection measures for individuals in two different, but related, situations: Contracts concluded by people under the influence of drugs or alcohol, or by people with temporary impairments of their decision-making abilities e.g. due to a severe shock or other trauma, can be declared as null and void in most legal systems. Secondly, governments have introduced extensive protection measures for consumers of goods and services that ensure specific safety standards as well as requirements for appropriate information of the consumers.
  2. It is important to recognize that legal changes pursuing the UN Convention in the area of legal capacity will probably affect all of these groups. Legislative change will not be limited only to people with disabilities.

## **People with intellectual disabilities and decision-making**

People with intellectual disabilities are not the only group of people with difficulties in exercising their legal capacity. Other important groups are people with age-related diseases that affect intellectual capacities, people with mental health problems, and people who are under the influence of medicines or drugs. All these groups share some of the common problems of exercising their legal capacity, but all have specific situations that need to be taken into account. The specific situation of people with intellectual disabilities in this context is that in most cases they have had an intellectual impairment from birth and thus neither they themselves nor their supporters can draw upon the experience of a non-reduced decision-making ability. Another uniqueness is the history of legal incapacitation, the resulting denial of fundamental personal rights and denial of self-determination by society that most people with intellectual disabilities have experienced. Decades of life under the assumption that they cannot take any decisions themselves and cannot live independently certainly have left a mark on the persons themselves, but also on their families, carers and the whole society. Deep-rooted assumptions and prejudices are the result of this situation. People with intellectual disabilities are from a very early start denied to the experience of decision-making, thus resulting on an inability to do this when they became adults. The concept of support-decision making goes with necessary reforms in all education programs from a very early age, to develop decision making abilities as well as trainings for professionals and families in order to empower this ability from a very early stage of life.

Looking objectively at the abilities of persons with intellectual disabilities, we have to conclude that many are quite capable to take decisions that concern their lives: what they like to eat or drink, what clothes to wear, what music or TV programs they like, with whom they want to live, or how they want to spend their leisure time. The objective of an inclusive approach is to extend these decision-making possibilities and options for each individual by making the life of society more accessible for people with intellectual disabilities.

Where people recognize that they need support, they first turn to their informal support networks. Many people with intellectual disabilities are quite adept in organizing their own circle of friends with or without disabilities, neighbors, colleagues, etc. to whom they turn when they need help. A colleague who helps to explain changes in public transport, a neighbor who talks with the landlord in case of problems with an apartment, or a friend with whom one buys new clothes are some examples. Action regarding legal capacity should seek to strengthen and extend these informal networks rather than substituting them by professional services.

Depending on the level of disability there will be larger or smaller areas of decision-making where a person with intellectual disability will need organized support and advice. Some people will need support in very simple daily decisions, whereas others will need help only with the big decisions that affect their lives. People with intellectual disabilities can learn how to take decisions. However, it is important to bear in mind that the risk of making mistakes should be fully accepted as a normal consequence of full legal capacity. The following core elements for a system of supported decision-making focus on providing this organized support without excluding the challenges and the difficulties mentioned in the previous paragraphs.

## **Key elements of a system for supported decision-making**

Supported decision-making as enshrined in the UN Convention, starts from the full and equal legal capacity of all citizens, even of those with severe and profound levels of disability. It then stipulates the right to receive appropriate support in decision-making, including the necessary safeguards:

### **1. Promotion and support of self-advocacy**

Being able to take one's own decisions requires training, support and role playing exercises. It requires also that family members, carers, professional staff and others recognize the ability of people with intellectual disabilities to take their own decisions. These are the objectives of the self-advocacy movement of people with intellectual disabilities who speak for themselves. This movement can provide invaluable support for peers with intellectual disabilities to take their own decisions.

Inclusion International therefore calls upon all States Parties

- to ensure that self-advocacy skills are included in the curricula of all schools;
- to create the conditions for self-advocacy groups and supporting self-determination
- to support and promote self-advocacy organisations.

### **2. Using mainstream mechanisms for the protection of the best interests of a person**

As it has been mentioned before, supported decision-making systems are not the only measures in place to protect the interests of a person. Consumer protection, consumer information, legal protection for tenants, rights of medical patients, rights of transport users, employees, etc. are but some of the areas where State Parties have already installed protection systems for citizens. People with intellectual disabilities are more vulnerable to be abused and therefore mainstream protection mechanisms should be made more accessible and more inclusive. It is preferable to use these mainstream mechanisms instead of special procedures developed for the protection of the disabled person's interests.

- Inclusion International therefore calls upon all States Parties
- to ensure that all existing structures and legal mechanisms for the protection of citizens in different areas of life are accessible for people with intellectual disabilities, accommodate the needs of people with disabilities and are able to take their interests into account;
- to disseminate information about the existence and work of such systems in accessible format to all people with intellectual disabilities and their supporters.

### **3. Replacing traditional guardianship by a system of supported decision-making**

As the principle of full legal capacity is established by Art.12, States Parties are required to develop a comprehensive system of supported decision-making and safeguards for all people with intellectual disabilities in law and in practice.

Inclusion International therefore calls upon all States Parties:

- to review all national laws in the light of Article 12 and to ensure that the right to self-determination and to equal recognition before the law by all persons without discrimination on the basis of disability is enshrined in the law.

- to abolish without delay all legislation and practices that (sometimes automatically) lead to a legal incapacitation once a person with intellectual disability becomes of age.
- to develop and establish a system for supported decision-making according to the core elements described below;
- to set up a plan to implement gradually the newly adopted supported decision-making system: new court decisions should implement the supported decision-making system; traditional guardianship measures on the basis of appropriate law reforms should be reviewed for all cases and should progressively be replaced by the supported decision-making system.

This system will take time to develop and would run the risk of becoming dysfunctional if all existing measures of traditional guardianship would be declared illegal at the same time, without the conditions in place that make supported decision-making effective for a particular individual. The system of guardianship and the system of supported decision-making should therefore exist in parallel during the period of time until the transition is completed.

#### **4. Supporting decision-making**

A law-based system of registered supported decision-making necessarily should only be applied when legally necessary – support in everyday life does not require such measures. However, especially volunteers who act as support persons often help the individual in a number of practical things in everyday life – from shopping to renovating the flat etc. Thus, registered supporters should focus on the main decisions of legal relevance that affect the life of a disabled adult: with whom and where they want to live, the choice of their work or day activity, medical decisions, establishing possibilities for leisure activities, and the choice of appropriate support services where needed. Registered supporters will need to observe a fine balance to provide their support to an individual in an empowering way that does not replace, but rather encourages the establishment of, existing support networks. The performance of the supporter should be regularly reviewed.

Inclusion International therefore calls upon all States Parties:

- to develop legislation that provides for supported decision-making for essential and important decisions of legal relevance, according to the needs and abilities of the persons.
- to ensure that assistance and training for supporters is available, including about rules and principles to guide the practical implementation of supported decision-making systems
- to ensure that training for people with intellectual disabilities is available.
- to encourage and support the creation of informal support networks for each individual.

#### **5. Selection and registration of support persons**

Any system of supported decision-making must meet the needs of the disabled individual. Support persons thus should be selected by the individual. It might be an advantage if they know the individual personally for a significant period of time. There should be the possibility to assign several support persons to one individual, this may be especially important for people with severe and profound intellectual disabilities where a group of support people who know the individual in different capacities may better match the support needs of a person. It is also important to assign to these support persons a legal status that allows them to be recognized as the officially authorized supporters of a specific person and legitimate their mandate.

Inclusion International therefore calls upon all States Parties:

- to establish criteria and selection processes for suitable support persons;
- to set up a registration system for these support persons that allows them to be officially recognized as supporter of the disabled individual:
- to ensure an obligatory and regular training for all registered support persons on all aspects necessary for providing adequate support and on the rules governing supported decision-making.
- to inform the population (especially some target groups e.g: bank staff, doctors, social workers, etc.) about the system of supported decision-making and identify what they should know.

## **6. Overcoming communication barriers**

Especially people with severe and profound intellectual disabilities find it difficult to communicate their wishes and preferences to other people. Some people, for example, communicate their well-being only through the rhythm of their breathing . Others may need communication devices or their communication partner may need to employ specific techniques to understand their wishes.

Inclusion International therefore calls upon all States Parties:

- to recognize that all forms of communication are valid and the way how people communicate should not be a reason to question their decision-making ability.
- to ensure that all people providing support for decision-making can receive a regular training in alternative and augmentative communication , in the use of communication technologies and in other communication techniques; to promote examples of good practice how communication barriers have been overcome.

## **7. Preventing and resolving conflicts between supporter and supported person**

There will be cases where persons with intellectual disabilities take decisions that supporters do not perceive to be in their best interest. This may include for example giving money to other people or to organisations, the purchase of goods that the individual cannot afford, or the cancellation of a work contract. While maintaining their right to take decisions up to and including the possibility to make mistakes, people with intellectual disabilities should also be effectively protected from abuse and personal harm.

Inclusion International therefore calls upon all States Parties:

- to oblige support persons to be able to demonstrate that they have informed the supported individual by all possible appropriate means about the consequences of any important decision;

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3 Inclusion International emphasizes the importance of one of the basic statements of communication theory for people with severe and profound disabilities: "You cannot not communicate!"

4. Augmentative and alternative communication (AAC) refers "to an area of research, clinical, and educational practice. AAC involves attempts to study and when necessary compensate for temporary or permanent impairments, activity limitations, and participation restrictions of individuals with severe disorders of speech-language production and/or comprehension, including spoken and written modes of communication" (ASHA, 2005, p. 1). Augmentative communication and alternative communication are terms used to refer to "nonspeech communication." Augmentative communication means partial dependency on nonspeech communication; Alternative communication means total dependency on nonspeech communication. AC devices can be used to supplement or replace verbal speech and vary depending on the person's skills and needs, as well as on the problems experienced by the person

- to create a mechanism to prevent abuses, including possibilities to ask for nullification of contracts in case a person was abused;
- in case of conflicts and to control to support persons, administrative (out-of-court) procedures that are easily accessible for the supported person as well as for the supporter should be created.
- to address the question of the liability and insurance of the supporter.

## **8. Implementing safeguards**

For good reason, the UN Convention is rather specific on the safeguards that must govern supported decision-making. An important principle is here that “the safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests”. This means that safeguards must be higher when a person has a higher degree of disability or high support needs or when a decision intervenes in a very essential way in the life of a person.

Inclusion International therefore calls upon all States Parties:

- to ensure without delay that the safeguards stipulated in the UN Convention are properly implemented in the field of supported decision-making legislation;
- to ensure that guardianship laws incorporate safeguards as long as they are in practice, until supported decision-making becomes available for every person with intellectual disability.