

# **Safeguards** in measures relating to the exercise **of legal capacity**

Inclusion Europe position paper



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Co-funded by the European Union.

The EU bears no responsibility for the contents of the report.

**2018** Inclusion Europe

# Introduction

It has been over ten years since the adoption of the text of the UN Convention on the Rights of Persons with Disabilities (CRPD). It demands in Article 12 equal recognition before the law for all persons with disabilities. The provision is clear in guaranteeing to all people with disabilities the right to enjoy full legal capacity on an equal basis with others, while also imposing an obligation on the states to provide them with support in exercising legal capacity<sup>1</sup>. A person's level of support needs should not be a barrier to obtaining support in decision-making<sup>2</sup>.

However, for people with intellectual disabilities access to these rights remains particularly difficult because of the still broadly accepted concept of substitute decision-making and the absence of proper arrangements to support people to take their own decisions.

Full legal capacity means being in a position to make decisions about one's life in big things and small. It affects the ability to find employment, the right to vote, the right to work, the right to marry and to hold parental rights, the right to free movement or the right to seek legal protection before courts. It also affects how people spend their money and what they do in their leisure time. Denial of legal capacity can even prevent an individual from requesting that their right to make decisions be restored<sup>3</sup>.

One of the most important reasons for the resistance against and slow implementation of the concept of full legal capacity for people with intellectual disabilities in the past ten years has been the concern for the safety and security of the person. People with intellectual disabilities are often perceived as especially vulnerable to abuse, manipulation and the possibility of taking decisions against their own best interests. This is a valid concern, even considering that the requirements for people with intellectual disabilities should not be higher than for anybody else – they also should have the opportunity to make errors and to learn from them.

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<sup>1</sup> Inclusion Europe published in 2008 a policy paper on the Key elements for a system of supported decision-making and in 2014 launched a website [www.right-to-decide.eu](http://www.right-to-decide.eu) to promote the different types of support for decision-making as defined in the General comment.

<sup>2</sup> CRPR Committee, General Comment n°1 §29.(a)

<sup>3</sup> See e.g. European Court of Human Rights, [Stanev v. Bulgaria](#), case no. 36760/06, judgment of 17 January 2012 or [Salontaji-Drobnjak v. Serbia](#), case no. 36500/05, judgment of 13 October 2009.

Article 12 of the CRPD recognises that individuals who are in need of support for making their decisions may be at increased risk of abuse. Therefore paragraph 4 of Article 12 requires safeguards to be put in place as safety measures to prevent it. Inclusion Europe and its members fully support this: **support for decision-making and safeguards must be developed hand in hand.**

The challenge is to define the concept of safeguards appropriately: how to respect the principle of autonomy, to protect people with intellectual disabilities and prevent abuse without being paternalistic. What are adequate safeguards in a supported decision-making model? Substitute decision-making certainly cannot be considered as a safeguard, as it has been sometimes argued or discussed.

This paper aims at providing Inclusion Europe's members and other interested stakeholders with an overview of the current understanding of "safeguards", its potential content and measures for consideration and standards for those safeguards.

*This paper was approved by the Inclusion Europe General Assembly 2017 in Prague.*

# Requirements for safeguards

Safeguards are safety measures put in place to ensure that persons with intellectual disabilities receive adequate and appropriate support to make their own decisions, while at the same time establishing the responsibility of supporters for their actions or the lack thereof. Safeguards may be seen as a form of individualised arrangements in the process of identifying ones' own will and preferences, but also as a set of measures to prevent supporters overstepping their duties or even abusing the person they support. Safeguards can never be used as an excuse to limit a person's legal capacity or to impose another person's will on them. The primary function or goal of a safeguard is to ensure that the person's rights, will and preferences are respected<sup>4</sup>:

*States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall 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 are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.*

Safeguards must be understood within the context of the idea of the "Dignity of risk"<sup>5</sup>. The issue of risk-taking is very important for people with intellectual disabilities, who may have been denied the process of choice and the opportunity to acquire decision-making skills. Respecting choices may carry some risks. However, in the context of supported decision-making, risk-taking means that adequate assistance and information must have been offered to the individual and that the individual was assisted to become aware of his or her responsibilities and of the implications of his or her choices. It means that risks should be limited and prevented by adequate support measures at individual level. And risk taking

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<sup>4</sup> CRPD Committee, General Comment n°1, § 20

<sup>5</sup> For the concept of „Dignity of risk“ see for example Piers Gooding, Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law, Psychiatry, Psychology and Law, 2013 Vol. 20, No. 3, pp. 431–451

must also be mitigated by safeguards against abuse at system level. Each society may have to answer the question of the limits of risk-taking and define a level of risks that are acceptable.

The following paragraphs analyse the eight main requirements for safeguards stipulated in this Article and take into account the subsequent interpretation available in the General Comment n°1.

## **Appropriate and effective to prevent abuse**

Any safety measure has to prove that it is appropriate and effective while fully complying with international human rights law. Decisions affecting the personal integrity of a person, such as for example sterilization or certain medical treatments, will require specific safeguards because of the high risk of abuse and the difficulty in taking such decisions as well as the important consequences for the person concerned. It is important to take into consideration possible abuse by both the supporters and by third parties.

## **Respectful of the rights of the person**

While ensuring that a person with intellectual disability receives all necessary support to make a decision, the framework for such support needs to respect all the rights of the person. The approach to organising support needs to be rights-centred. The requirement to respect rights of a person overlaps with the requirement for the support to be in compliance with international human rights law, but goes beyond that.

It is important to note that safeguards cannot limit any rights enshrined in the CRPD, such as the right to vote (art. 29), the right to marry and found a family (art. 23), the right to choose where to live (art. 19), access to justice (art. 13) and others.

## **Respectful of the will and preferences of the person**

Against the background of the rights of the person, in order to support a person with disabilities in their decision-making process the first necessary step needs to be to establish the genuine will and preferences of the person.

This process is key to ensure that the decision-making process is one in which the person with intellectual disability is supported to make their own decision, rather than this decision being imposed upon them by persons in their surroundings. The respect for will and preferences is therefore central to the paradigm shift and replaces the best interest principle which prevails in substitute decision-making models.

In order to identify the will and preferences of the person it is imperative to include the person concerned in every step of the process of establishing support. Furthermore, the person must also be involved in the process of making every decision which concerns his/her life.

Identifying will and preferences may be more or less challenging depending on each person, his or her support needs, communication mode as well as access to close and trusted persons. As a guideline in situations where will and preferences cannot be clearly determined, only once significant efforts have been made, the Committee introduced the notion of “**best interpretation of will and preferences**”. This provides the possibility to assess will and preferences, while acknowledging that there is no certainty about the person’s will and preferences.

Safeguards must also be in place in order to address situations where a person’s expressed will or preference would lead to serious harm. In case of a decision leading to serious harm, state intervention should be strictly scrutinized and monitored to avoid violations of human rights, such as forced institutionalization, forced hospitalization or forced treatment. It is necessary to set up standards for exceptional cases only and to make sure that these standards do not discriminate directly or indirectly against people with disabilities.

Safeguards must also be in place to address the issue of conflicting will and preferences. Clear steps should be defined to help resolve the conflict including the best interpretation of will and preferences and standards for state intervention, in case this situation can cause serious harm.

## **Free of conflict of interest and undue influence**

Conflict of interest in this context can be defined as a real or seeming incompatibility between ones private interests and ones duties towards a supported person<sup>6</sup>. A conflict of interest generally refers to a situation where the impartiality and objectivity of a decision, opinion or recommendation is or might be perceived as being compromised by a personal interest held or entrusted to a given individual. Undue influence is the improper use of power or trust in a way that deprives a person of free will and substitutes another's objective<sup>7</sup>. Undue influence is characterized as occurring where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation<sup>8</sup>. Support for decision-making needs to be free of both.

The difference between the two categories stems from their consequences. When there is conflict of interest, there does not necessarily have to be consequences for the person concerned. It is enough that the decision maker and the supporter have or seem to have different interests on the subject matter. When there is undue influence, the consequence has already taken place. The person concerned has formed a decision, but that decision is not genuinely free. Conflict of interest may or may not lead to undue influence.

## **Proportional and tailored to the person's circumstances.**

Each person needs to be given the kind and amount of support they need, and this should to be informed by that person's individual circumstances. Support needs should be identified early on and should develop as the person's situation evolves. Support cannot be organised on a one-size-fits-all principle.

The person concerned needs to be fully involved in the assessment of the support needed, as well as able to request its review and participate fully in the review process. Person-centred planning should be at the core of determining personal circumstances.

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<sup>6</sup> Black's Law Dictionary, Eighth Edition, Second reprint, 2007.

<sup>7</sup> Ibid.

<sup>8</sup> CRPD Committee, General comment No. 1, *supra note 4*.



People may need support in some areas of life only. Health care and finances/assets management may require specific instruments which may be combined with supported decision-making agreements or not, depending on each individual situation.

## **In place for the shortest time possible**

People with intellectual disabilities may need some sort of support throughout their entire life. As support needs will vary over time, different kinds of measures relating to the exercise of legal capacity may be required.

People acquiring more autonomy should be able to reduce the amount or the area(s) of support where they can be autonomous. On the contrary, elderly persons with intellectual disabilities may need additional support while dealing with age-related problems or illness.

Capacity should be understood as a dynamic notion taking into account not only current capacity but also potential capacity. For example: support for managing finances can be provided but also training about how to manage money, if the person is willing to acquire more autonomy in this field.

Nonetheless, a support measure can never be imposed on an individual. As soon as a specific measure becomes unnecessary or unwanted by the person concerned, it needs to be removed.

To have the measure in place for the shortest period of time, it is necessary to either limit the duration at the very beginning, or for the more long-lasting arrangements, to have regular reviews of the measures in place.

## **Subject to regular review by a competent, independent and impartial authority or judicial body**

Measures to support a person in their decision-making process need to be determined and then supervised by a competent, independent and impartial authority.

- **Competent** should mean that the body putting support into place is made of experts who have sufficient knowledge of human rights and other legal requirements in place to protect rights of

persons with intellectual disabilities, and a understanding of the potential and particular needs of the person in question.

A Court should be involved only in case of conflicts over supported decision agreement or specific decisions which exceed the frame of such agreements, such as those affecting personal integrity or involving important assets.

- **Independent and impartial** is to mean independence vis-à-vis the other bodies and impartiality vis-à-vis other interested parties. An independent and impartial body needs to be in a position to make their own unbiased decision, which will not be influenced by opinions, attitudes or preferences of anyone else but the person who will receive the support themselves.

It needs to be ensured that the support in place is regularly reviewed, the need for support discussed and, eventually, amended or removed. These regular reviews need to take place with sufficient frequency, not to be allowed to be in place longer than absolutely necessary, and not less frequent than once a year.

Persons with intellectual disabilities may, at any moment, themselves request a revision, change or withdrawal of the entirety or parts of the support system.

## **Proportional to the degree to which such measures affect the person's rights and interests**

The principle of proportionality requires that there is a reasonable relationship between a particular objective to be achieved and the means used to achieve that objective. Any measure aimed to support decision making needs to be created to ensure that it is the necessary amount of support that a particular person needs. The person needs not to receive too little or too much of the support. The requirement of proportionality needs to be present throughout the process and needs to be built into the supervision mechanisms and revised each time the support is revised.

The balance needs to be struck between the measure suggested and the potential consequence of the decision for a person's life. For example, support for doing daily chores, managing finances or support to start a family will each need varying levels of involvement of different supporters and varying levels of engagement of the person concerned or other possible actors.

# Practical implementation of the requirements

Neither the CRPD itself nor its General Comment No.1 provide a clear set or list of safeguards, but only the above basic requirements for safeguards. On the basis of these requirements, there is ongoing discussion about what safeguards are necessary in supported decision-making regimes.

Inclusion Europe and its members recognise the vital importance of safeguards for people with intellectual disabilities and **advocate strongly for the further development and implementation of safeguards to protect people with intellectual disabilities in supported decision-making regimes.** It is important to consider safeguards in all aspects of decision-making.

## **The right to support in decision-making must be recognised in national law**

The right to support in exercising legal capacity (as stated in Article 12 §3) should be recognized by the law so that it guarantees who (within the State structure) has the obligation to provide support for decision-making. A legal framework should also include a list of legally formalised types of support (they could be named supported decision-making contracts or representation agreements) to guarantee the right to use these instruments. The law should also include provisions on the obligation of third parties to provide reasonable accommodation in support for decision-making, such as accessible information, including easy-to-read material, alternative communication, the provisions of interpreters, informal assistance of a trusted person, etc.

If the right to support and the right to reasonable accommodation are guaranteed by national legislation, the absence or inadequacy of these provisions can be appealed or challenged by persons with disabilities and/or their representatives.

## **Legal mechanisms preventing abuse in critical decisions should be established**

In addition to the basic right to support in decision-making, it is essential to develop legal mechanisms that can control the support given for specific decisions and prevent abuse in essential decisions which

may affect the personal integrity of a person or the management of significant amounts of financial assets. Safeguards preventing abuse could include the following measures<sup>9</sup>:

- A legally appointed Monitor could be involved in these kinds of decisions, supervising the decision making process and controlling that the will and preferences of the person have been genuinely searched for, interpreted and respected.
- A specialised Tribunal could validate the decision based on certain criteria and evidence that should be provided by the support person(s) and other trusted relations of the person concerned.

## **Defining and organising supported decision-making in a person-centred way**

Support cannot be organised on a one-size-fits-all principle. Each person needs to be given the kind and amount of support they need, and this should to be informed by that person's individual circumstances. Support needs should to be identified early on and should develop as the person's situation evolves. The presumption of capacity of each person should however be the starting point.

The person concerned needs to be fully involved in the assessment of the support needed, as well as able to request its review and participate fully in the review process. Person-centred planning should be at the core of determining personal circumstances. A trusted person / independent advocate / alternative communication facilitator could play a role in situations where the person cannot (clearly) express his or her will. They could guarantee that all efforts have been made to respect the rights and to interpret, in the best way possible, the will and the preferences of the person in this process, and that any conclusion were based on them, providing evidence of the actions taken.

People may need support in some areas of life only. Health care and finances/assets management may require specific instruments which may be combined with supported decision- making agreements or not, depending on each individual situation.

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<sup>9</sup> For more details about safeguards on this point see Micheal Bach and Lana Kezner, 2010. A New Paradigm for Protecting Autonomy and the Right to Legal Capacity, Report to the law Commission of Ontario, available at: <http://www.lco-cdo.org/disabilities-commissioned-paper-bach-kerzner.pdf>

Person centred planning instruments can help defining the areas in which an individual needs support and how this support can be provided. Specific or difficult decisions may require an assessment of the support needs for that specific decision.

Therefore, people with intellectual disabilities should have the right:

- to access mechanisms that can support their autonomous life in the community, including access to finance and property, e.g. trust funds<sup>10</sup> (financial planning and property management for persons with intellectual disabilities, when families want to create a fund or make assets available for the person's use and benefit or when the individual requests such support.)
- to consent to medical treatment with support (mental health laws need to be revised in the context of the CRPD to strictly frame and scrutinize state intervention in this field)

The principle of proportionality requires that there is a reasonable relationship between a particular objective to be achieved and the means used to achieve that objective. Any measure aimed to support decision-making needs to be created to ensure that it provides the necessary amount of support that a particular person needs. The requirement of proportionality needs to be present throughout the process and needs to be built into the supervision mechanisms and revised each time the support is revised.

Persons with disabilities should have the possibility to contest and complain about supported decision arrangements if there are not satisfied with the way these arrangements have been determined and organised.

## **Monitoring and reviewing support arrangements**

It is an important basic principle that the supported person must be involved fully in every step of establishing support arrangements. Persons with intellectual disabilities also may, at any moment, request a revision, change or withdrawal of the entirety or parts of the support arrangements themselves.

In relevant cases, such as for people with higher support needs or without verbal communication, a Monitor could be appointed along with supporter(s). The role of a Monitor is not to provide support but

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<sup>10</sup> <http://www.right-to-decide.eu/2014/12/trusts/>

to guarantee good ongoing support. The Monitor should oversee the actions and decisions of supporters and should be able to talk regularly to the supported person. In his or her capacity, the Monitor could alert or intervene, if he/she thinks that the rights or the will or preferences of the persons have not been respected or that the person has been abused.

To have the support arrangement in place for an adequate period of time, it is necessary to either limit it in time at the very beginning, or for the more long-lasting arrangements, to have regular reviews of measures in place. This approach was taken in Germany, where the revision of support is done every year with the participation of the person concerned. It is important, however, to avoid a high administrative burden – the revision of support arrangements should be effective and supportive of the autonomy of the individual and not be degrading for the supported person (for example by requiring a medical assessment or other stressful experiences). It needs to be ensured that the support in place is regularly reviewed, the amount of adequate support discussed and, eventually, amended or removed. These regular reviews need to take place with sufficient frequency, not to allow safeguards to be in place longer than absolutely necessary, and not less frequent than once a year.

## **Establishing the genuine will and preferences of a person**

In order to support a person with disabilities in their decision making process the first necessary step needs to be to establish the genuine will and preferences of the person. This process is key to ensuring that the decision-making process really supports the person with intellectual disability to make their own decision, rather than that this decision being imposed upon them by persons in their surroundings. The respect for will and preferences is therefore central to the paradigm shift and replaces the best interest principle which prevails in substitute decision-making.

Identifying will and preferences may be more or less challenging depending on each person, his or her support needs or communication mode. It will also depend on the presence of close and trusted person(s). Where will and preferences cannot be clearly determined, after sufficient significant efforts have been made, the notion of “best interpretation of will and preferences” gives the possibility to the supporters to provide an answer based on the best interpretation of will and preferences, acknowledging that they are not certain about the person’s will and preferences.

Inclusion Europe members understand that the interpretation of will and preferences does not qualify as supported decision-making but is rather a process of ‘facilitated decision-making’ or ‘co-decision-making’. ‘Best interpretation’ rather than supported decision-making, backed by evidence of the person’s will and preference, should only occur by exception. The instances in which decisions are facilitated in this way should be minimised and carefully scrutinised. The acceptance, even in limited cases, of someone’s interpretation of a person’s will is controversial and has the risk of leading back to substitute decision making if not kept under review.

For this reason, the interpretation of will and preferences should occur according to the following standards:

1. The participation of the person in the interpretation process.

1. Involving trusted persons or other persons who are important in the life of the supported person (along with an independent advocate or communication facilitator in those cases where a person has a very poor network)
2. Taking into account the personal history, records of previous decisions, previous preferences and other information available about the person.
3. Reviewing the decision at a right and reasonable time.
4. Acting on the basis of the principles that underpin human rights and the core principles of ethical practice such as fairness, independence, beneficence, trustworthiness, veracity, confidentiality.

## **Establish rules for support persons**

A list of duties and a clear scope of liability of the support persons should be part of the legislation. Supporters should also be required to report on any conflict of interest they find themselves in, or when there is a risk of it with anybody else in the circle of support. If the figure of the Monitor is included in the law, their function and duties should also be defined.

Rules for support persons can include compulsory training, ethical code or principles, methodological guidance, as well as practical recommendations but also measures or techniques for self-assessment and supervision.

## **Establish accessible complaint mechanisms**

Supported persons with disabilities should have access to a simple out-of-court complaint mechanism to challenge their supported decision agreements but also to complain about the way a supporter is acting. Such a mechanism (e.g. a Resource Centre, a relevant disabled persons' organization or NGO...) should provide mainly mediation as primary dispute resolution mechanism and in case of failure, it should support people with disabilities to go to court.

Such Resource Centres should also provide specialised legal counselling (State-funded to guarantee its accessibility to all).

Also the independent assessment of ongoing support arrangements could be carried out by a Resource Centre. It could be the primary place for people with disabilities to complain (as they would therefore know the Resource Centre), in case they are in conflict or unsatisfied with their supporters.

Similarly, as recommended by the CRPD Committee, a mechanism for third parties to challenge the action of support persons should be in place, if there is evidence that they are not acting on the basis of will and preferences or are neglecting the person who need support in decision-making.

There may be situations where a person with an intellectual disability may wish to make a decision on his or her own but is challenged by a third-party representative. In this case again, this person should have access to adequate information, mediation and out-of-court dispute resolution mechanisms. The role of such a mechanism could also be to advise on the necessary reasonable accommodation arrangements, that can be made and which may be sufficient to allow the person to make a decision on his or her own.

## **Create a national system for the legitimation of formal support arrangements**

In order to make it possible for third parties, such as banks or medical staff, to verify if someone is a legitimate supporter of a person, it is important to establish a place where they can track supported



decision arrangements (contracts, judgments, etc.) with the names of the supporters. A National Registry should exist to create and maintain such a registration system. Such a registry should be mandatory but the access should be limited to third parties who have a legitimate interest to control who can support whom.<sup>11</sup>

Notary chambers are often also used for keeping a registry, for example of advance directives. This could be extended to supported decision-making agreements. Ministries are also responsible for some other types of registry. A registry of supported decision-making agreement may also be run by a State authority.

If no registry is created, other forms of legitimation should be established. It is important to ensure that both the registry or any other form of legitimation respect the right to privacy and do not allow third party to access to unnecessary information (e.g.: diagnosis, medical or other strictly personal information).

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<sup>11</sup> The Nidus Personal Planning Resource Centre ([www.nidus.ca](http://www.nidus.ca)) is a non-profit, charitable organization. Nidus is a Resource Centre specializing in Representation Agreements (supported decision-making agreement) and it also operates a centralized Registry for personal planning documents. Nidus provides counselling in personal planning and making arrangements for people who need help managing their affairs, because of illness, injury, or disability. Nidus has particular expertise in preparing individualized Representation Agreements and supporting people in using this instrument.

More about Nidus: <http://www.right-to-decide.eu/2014/08/nidus-personal-planning-resource-centre-and-registry/>

# Recommendations

Safeguards for supported decision making are far from a simple notion but are crucial to ensure full enjoyment of the rights protected by Article 12 and consequently any other rights by persons with intellectual disabilities. Further discussion will be needed to develop adequate safeguards while supported decision-making becomes a reality in more and more countries.

Inclusion Europe puts forward the following recommendations for safeguards in supported decision-making:

- The right to support in decision-making must be recognised in national law.
- Access to information and reasonable accommodation must be guaranteed by law.
- Current mental health law and any legal form of forced hospitalization/forced treatment/deprivation of liberty should be reviewed and modified in the context of the CRPD.
- People with intellectual disabilities, their families, their supporters and their representative organisations should be involved in the whole policy and legislative process to create appropriate support arrangements, as well as in their consequent evaluation.
- Self-advocacy and peer-to-peer support should be promoted to develop decision-making competences.
- People with disabilities must be allowed the dignity of risk within supported decision-making arrangements.
- Legal mechanisms preventing abuse in essential decisions should be established in form of specialised out-of-court and/or court mechanisms.
- Mechanisms for establishing and monitoring support arrangements must be put in place, for example in form of a Resource Centre, providing information, advice about supported decision-making and mediation services.

- More procedures should be developed to help supporters to establish the genuine will and preferences of a supported person in a person-centred way.
- Monitors could be appointed where necessary to oversee the support process and relationship
- Clear standards, ethical principles and reviews should be set up for the exceptional use of facilitated decision-making, when best interpretation of will and preferences has to occur.
- Accessible complaint mechanisms must be established out of court in order to mediate and facilitate an adequate relationship between supporter and supported person.
- Rules for support persons should be further developed in order to ensure the necessary safeguards for the supported person.
- National registries or other forms of legitimation of support arrangements need to be created and made accessible.

In addition to promoting the above safeguards with other stakeholders, Inclusion Europe itself will focus in the coming years on further developing three essential safeguards from the list above:

- Models for support arrangements will be collected, analysed and published to serve as examples on how safeguards can be implemented in such arrangements.
- Inclusion Europe will collect and further develop procedures to help supporters to establish the genuine will and preferences of a supported person in a person-centred way.
- Inclusion Europe will further develop rules for support persons in order to ensure the necessary safeguards for the supported person.