Preamble

These principles aim to demonstrate concrete measures which countries can take to implement the support model of legal capacity set out in Article 12 of the UN Convention on the Rights of Persons with Disabilities. Although legal capacity touches upon a myriad of laws which may require reform (criminal law, consent to treatment, family law, property law, etc.) the primary focus of the PERSON project is on reform of legal incapacity regimes, or substitute decision-making mechanisms, such as adult guardianship, while acknowledging the interdependent and interconnected relationship of all human rights – and recognising that broader reform including reform concerning the right to liberty, to vote, to marry, and to consent to sex (to name a few), must also be achieved, and will enhance the equal enjoyment of the right to legal capacity of persons with disabilities.

Since the primary focus of the PERSON project is on reform of legal incapacity regimes such as adult guardianship, these principles, although applicable to all human persons, may require modification or adjustment in the context of children (including children with disabilities). This is reflected in the language of the Convention itself; Article 7(2) on children with disabilities states that in “all actions concerning children with disabilities, the best interests of the child shall be a primary consideration”, whereas Article 12 avoids any reference to “best interests” as a guiding principle in decisions regarding the exercise of legal capacity. These tensions cannot necessarily be resolved in the context of the PERSON project, although regard will be had to the need to support children with disabilities in the exercise of their legal capacity throughout the project. Children with disabilities should be supported to develop decision making skills to prepare them for the exercise of legal capacity when they reach the age of majority in their country.
All regimes of substitute decision-making including partial guardianship must be eradicated.

The UN Committee on the Rights of Persons with Disabilities has repeatedly stated in its Concluding Observations on Article 12 that States Parties must “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.” The PERSON project will aim to ensure that law reform in the partner countries reflects the support paradigm of legal capacity enshrined in the UN Convention on the Rights of Persons with Disabilities.

All denials of legal capacity, which result from an assessment or perceived deficit in mental capacity, must be abolished.

People with disabilities have experienced discrimination in the denial of their legal capacity, when compared with non-disabled people. This type of discrimination has particularly affected individuals with intellectual, cognitive and psycho-social disabilities. In many countries, a person’s legal capacity can be removed based on a perceived deficit in mental capacity (decision-making ability). Article 12 of the CRPD states that all persons with disabilities “enjoy legal capacity on an equal basis with others.” This means that a decision-making disability should not result in the removal of the individual’s legal capacity, even if the removal is temporary or related to a specific decision.

An individual’s mode of communication must not be a factor in determining legal capacity.

All individuals communicate differently, and some, including people with decision-making disabilities, may communicate in ways that very few people can understand (including non-verbal communication, signs, gestures, and body language). This may present challenges in interpreting or discovering an individual’s will and preferences in respect of a particular decision. However, the use of non-standard, or unconventional, means of communication should not be a factor in determining the person’s level of decision-making ability, or used as a reason to deny the individual legal capacity.
An individual’s support needs must not be a reason for depriving a person of legal capacity. The availability of social services and supports cannot be made conditional on the deprivation of legal capacity.

Persons with intellectual, cognitive and psycho-social disabilities have suffered multiple discrimination and double standards have been applied when compared to persons with other types of disabilities. While the high need for support of persons with physical or sensory disabilities does not always lead to the deprivation of their other rights, such as the right to work, such high need for support has been used against persons with intellectual, cognitive and psycho-social disabilities to deprive them of their legal capacity, and consequently all their rights. In addition, there is a strong connection between social service provision and deprivation of legal capacity in many countries. Article 19 of the UN Convention of Rights of Persons with Disabilities calls for enabling people with disabilities to live in the community on equal basis with others and must be read in conjunction with Article 12 of the same Convention. People with disabilities have the right to access social services, and this right should not be contingent on the denial of legal capacity as a pre-condition for using such services.

Supports to exercise legal capacity must be legally recognised.

Article 12.3 of the UN CRPD requires States Parties “to provide access by persons with disabilities to the support they may require in exercising their legal capacity.” Supports to exercise legal capacity can take many forms. Some individuals may simply require accessible, easy to understand information relating to decisions. Others may need more time to make a decision, or informal support from a trusted person. Formal supports should also be available and legally recognized. This could include advocate supports (e.g. self advocacy, peer advocacy and independent advocacy), the ability to plan in advance (e.g. advance care directives, enduring powers of attorney) and formal support agreements (e.g. representation agreements, supported decision-making agreements). Legal recognition of the supporter(s) formally chosen by the individual must be available and accessible, and the State has an obligation to facilitate the creation of these supports, particularly for people who are isolated and may not have access to naturally-occurring supports in the community. The legal recognition of supporters must include a mechanism for third parties to verify the identity of a support person as well as a mechanism for third parties to challenge a decision of a supporter if s/he believes the supporter is not acting based on the will and preference of the individual.
Assistance in decision-making must not affect any other fundamental rights.

The use of assistance in decision making should not affect the rights of persons with disabilities to independently exercise fundamental human rights that are closely connected to their identity and right to self-determination. This is especially so for the right to vote, right to marry (or establish a civil partnership) and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and the right to liberty. Article 3 of Universal Declaration of Human Rights guarantees everyone “the right to life, liberty and security of person.” However, many people with intellectual, cognitive and psycho-social disabilities are placed in residential institutions or psychiatric hospitals by their legally appointed guardians against their will or through the lack of informed consent. The placement of individuals in institutional care by their guardians has been condemned by the European Court of Human Rights, which has also on multiple occasions emphasized a need to establish procedural safeguards in order to avoid simultaneous deprivation of freedom and deprivation of legal capacity.

All forms of support to exercise legal capacity (including more intensive forms of support) must be based on the will and preference of the individual, not on the perceived/objective best interests of the person.

The support paradigm enshrined in Article 12 of the UN CRPD can be realized in a number of ways – but any support model must have at its core the goal of realizing the will and preferences of the individual. It is this concept that distinguishes the support paradigm from substitute decision-making. Regimes of substituted decision making impose an external decision-maker on an individual who has been denied legal capacity, where the decision-maker acts in the objective or perceived ‘best interests’ of the individual, rather than acting in accordance with the individual’s wishes. Where an individual’s will and preference is unknown and a decision needs to be made, the support model may provide for an external decision-maker to be appointed. However, the goal of that decision-maker will be to discover the individual’s will and preference and act accordingly. This means that a support person can never be imposed against the will of the individual, and a last resort decision-maker may only be appointed where the will and preferences of the individuals are unknown, and cannot be discovered, after significant efforts have been undertaken to do so. It will be a matter for each State to develop clear criteria and standards on what constitutes ‘significant efforts’ to discover an individual’s will and preferences and to ensure that these standards are applied consistently to avoid the appointment of last resort decision-makers. It is also important to recognize that a person’s will and preferences may change over time, and supports for the exercise of legal capacity should reflect this. Within the support paradigm, there should be room for time-limited and least-restrictive emergency interventions, but these interventions must be strictly safeguarded and monitored and must not amount to a loss of legal capacity. The use of any emergency procedures must be directed towards restoring and augmenting the person’s legal capacity.
The person must have the right to refuse support or end the support process at any time they choose.

It is of fundamental importance in the supported decision-making process that collaboration between persons with disabilities and support-providers is based on the free will of the persons concerned. No decision can be made with the support of the other person without collaboration that is based on free will and informed consent. People with disabilities have the right to refuse support as whole, or just some levels of supports, or to end such form(s) of support at any time they chose and with no need to explain the reasons for such decisions. Connected to Principle 4, there must be no negative legal consequences imposed on persons who refuse support in decision-making.

The same principle of informed consent should apply to the individual’s right to refuse any healthcare intervention, including psychiatric treatment, even where these interventions have been conceptualised as a form of support. According to Article 14 of the UN Convention on the Rights of Persons with Disabilities “the existence of a disability shall in no case justify a deprivation of liberty”; this has been interpreted by the Committee on the Rights of Persons with Disabilities to include a prohibition on involuntary psychiatric treatment.

There must be safeguards for all processes connected to legal capacity and supports to exercise legal capacity. The goal of these safeguards is to ensure that the person’s will and preferences are being respected.

Two main types of safeguards are required to implement this principle. First, safeguards to prevent the deprivation of legal capacity must be in place. Second, safeguards to ensure that the person’s human rights are protected throughout the support process. In order to safeguard the rights of people with disabilities, there must be monitoring of support arrangements. These should include check and balance systems to ensure that the support person is reflecting the individual’s will and preferences, and not imposing their own perspective of what is in the individual’s best interests. In a true support model it is not possible to remove an individual’s legal capacity. Nevertheless, if an actor within the support system is acting inappropriately, an individual may be at risk of having her will and preferences undermined, ignored or displaced and safeguards must be aimed at preventing this. The support paradigm strives to realize not only the right to equal recognition before the law, but also the rights to freedom from ill-treatment, abuse, and neglect, as well as the rights to health and life. Safeguards must also operate to prevent exploitation and abuse of individuals using supports to exercise their legal capacity, and undue influence by support persons or others.
All information and processes related to legal capacity and support options must be accessible to the individual and accommodate their specific needs.

In order to fully realize the support paradigm, individuals must be made aware of their rights and have the tools to assert and enforce them. This means that information on available and recognized supports that can be used in the exercise of legal capacity must be accessible to all, including people with disabilities. It also means that public information more generally, and specific information which an individual might need in order to make a decision, should be available in a format that is accessible to the individual, and can be easily understood by them. In addition, support people must have access to training in how to provide support in decision-making that meets the particular needs of the individual – this includes formal and informal supporters. There must also be an accessible authority for people to go to when there is a conflict or concern with the supported decision-making relationship.