PLAIN ENGLISH

Principles and Key Issues for Legal Capacity Legislation

Preamble

These principles aim to reflect the spirit and values of the new capacity law, which is replacing law dating from 1871. Everyone should be presumed to have the capability to make decisions. The main focus of the new law must be to support people to make their own decisions.
The new law must include three different levels of support: (i) The first level is where a person has the ability to make decisions with only minimal support e.g. easy to read information. (ii) The second level is 'supported decision-making', where a person is supported by someone they trust to make a decision, and (iii) the third level is 'facilitated decision-making', this is used as a last resort where the person's will and preferences are not known. Here, a representative has to determine what the person would want, based on what they know about that person and on their best understanding of their wishes.

Principle 1

All human rights apply to all people equally – without discrimination on the basis of disability. This includes everyone's right to make choices and decisions about their life.

Key issues:

a. New capacity law should respect a person's independence, dignity and freedom to make their own choices; without discrimination on the basis of disability.
b. The new law must focus on recognising each person's right to self-determination. It should focus on encouraging supports to achieve autonomy and not on deficits. Focusing on supporting people to make their own decisions will reduce the need for other people to make decisions on behalf of people with disabilities.
a. Mental health law should be amended in light of the new capacity law, respecting and promoting the rights of people with mental health problems.
b. In the context of persons involuntarily detained or treated under mental health legislation the CRPD requires respect for their legal capacity including for their expressed will and preferences. Legal capacity and mental health legislation need to reflect the evolving jurisprudence of the CRPD Committee, in particular in relation to Article 14 (liberty and security of person) and Article 17 (protecting the integrity of the person). Sufficient safeguards, such as

regulation, reviews and tribunals, should ensure the person's human rights are fully respected.

Principle 2

The values and principles of the UN Convention on the Rights of Persons with Disabilities must be reflected in the capacity law.

Key issues:

a. The name of the law should be non-discriminatory. Taking into account the Convention, the name of the law should be 'legal capacity' rather than 'mental capacity'. (See key issue 3a for more details.)
a. This law must protect people's rights to make decisions about all aspects of their lives – as outlined in Article 12 of the Convention – including (for example) decisions about healthcare, finances, relationships and where and with whom to live.
b. For this law to be effective it must ensure it protects the individual rights as outlined in the Convention. These include (among others) the right to choose where and with whom to live (Article 19), the right to freedom from violence and abuse (Article 16), the right to consent to the most effective and efficient healthcare treatment (Article 25), respect for privacy (Article 22) and the right to be able to access justice (Article 13).
d. People with disabilities and the organisations that represent people with disabilities should be involved in the process of writing the law and how it should be implemented, as outlined in Article 4 of the Convention.

Principle 3

All adults have a right to make decisions for themselves and to exercise their rights ('legal capacity') and must be given the supports they need to be able to make decisions.

Key issues:

a. This means that instead of the focus being on guardianship and other people making decisions in the 'best interests' of the person, the top priority of the new law must be to make sure people are supported to make their own decisions whenever possible. The new law should not take away people's rights to make their own decisions. It should only assess the level of support a person needs to make a decision and ensure this is provided.
b. When a person needs support to make a decision, these supports should make sure the person's will and preferences are clearly put

forward. This can be done by the individual, or a community of support, chosen by the person, which has a meaningful relationship with the individual.

c. People with disabilities have a right not to have their decision-making skills interfered with or reduced.

Principle 4

People who need support to make decisions have a right to be provided with that support by the State. For example, advocate supports should be recognised and assist the person in understanding options and expressing their will and preferences.

Key issues:

Different levels of support should be provided within the law depending on what the person needs to be able to make decisions. For example:

a. Reasonable accommodation should be made to help the person understand the decision. Different ways of providing information must be explored (including sign language, alternative communication, flexibility with regard to time and location for delivering information, pacing, repetition, and a trusted source for information, etc.).
b. There should be a range of advocacy supports, including state-appointed advocates with statutory powers, as well as other forms of individual advocacy (e.g. citizen advocacy, peer advocacy, self advocacy support).
c. Other social or community supports should be used to help the person express their will and preferences.
d. All supports must respect the will and preferences of the person.
e. The person must have the right to end the support process if and when the person wishes.

Principle 5

The law should allow people to plan in advance and have such decisions protected in law. There should be awareness raising and education around the option to make plans in advance.

Key issues:

a. Advance planning should be an option that is available to all (including planning in relation to mental health). Awareness-raising and education around advance planning as an option is a key part of a supported decision-making model.
b. Advance planning should be subject to safeguards which ensure that

the decision to appoint a representative reflects the will and preferences of the person and that the representative does not abuse his position or act outside the prescribed role.

c. There should be a meaningful ability to challenge and reverse the appointment of a representative in advance planning.

Principle 6

A person retains their fundamental rights e.g. to vote, marry, etc, even if they are getting support to make a decision or someone else is making a decision for them.

Key issues:

a. In many countries capacity law includes the denial or restriction of certain fundamental rights. In the new capacity law these rights should not be restricted.

Principle 7

Strict safeguards must be in place to protect the human rights of people who are supported in making decisions, or who have someone making a decision for them.

Key issues:

a. These safeguards should include; awareness-raising about supported decision-making, and education and training for all involved (parents, service providers, lawyers, doctors, etc.)
b. There should be routine checks on supported and facilitated decision-makers (for example, looking at whether the decisions made represent the will and preferences of the person, as far as these can be understood).
c. Protections in law should be introduced so adults with decision-making difficulties are not put at risk or exploited.
d. People having difficulty making decisions should have the right to legal representation within all formal processes relating to capacity.

Principle 8

Decisions made by someone else for a person is a last resort when all supports have been considered (facilitated decision making). It should only apply for specific decisions and for the length of time necessary for that purpose.

Key issues:

A nominated person can make a decision for someone when it has been

satisfied that reasonable accommodation and supports have been fully considered but these supports have not led to a decision, and the will and preferences of the individual are not known. In these cases of last resort of facilitated decision making, the decision must be based on the will and preferences of the person. This means that where the will and preferences of the person are not known, the facilitated decision-maker has to determine what the person would want, based on all the information they have about the person (spending time with the person and trying all forms of communication, speaking to those who know the person well, thinking about the person's life, their likes and dislikes, etc.). People who know the will and preferences of the person, or have a meaningful relationship with them, and so could help to express their view, should be given a chance to contribute to the decision. Where someone else is making more than one decision about more than one aspect of a person's life, appropriate ways to do this must be carefully considered. Appropriate supports should continue to be provided even after a facilitated decision-maker has been appointed as this could augment the person's decision-making capability.

The following things must have been attempted before facilitated decision-making can apply.

a. The decision-maker must have made the best effort to communicate with the person, through all possible means, including, for example, unconventional or alternative communication (e.g. body language, non-verbal communication, etc.).
b. The decision-maker must have made every effort to understand the person's will and preferences, including by, for example, making an effort to build a relationship with that person.
c. If there is no existing support network for the person who could help with the decision, one should have been created if possible.
d. Every effort must have been made to provide information in a manner that the person can understand and all means of support (including advocacy) should have been provided in order to help the person and/or the network to make a decision.

Principle 9

All information, processes and procedures must be easy to understand, must have the person at the centre of the process, and must meet that person's individual needs. This means that a court-based system which determines capacity is not appropriate.

Key issues:

a. Supports that help someone to make a decision should be made as easy as possible for people to use. This will ensure that other people making decisions for a person ('facilitated decision-makers') is a last resort, rather than the first option.

Principle 10

When somebody else is being appointed as a decision-maker for a person ('facilitated decision-making'), the person should have the opportunity to take part in the process and be fully represented, keeping in mind that a facilitated decision-maker should only be appointed where the will and preference of the individual is not known.

Key issues:

a. Those making decision for someone else (facilitated decision makers) should be independently appointed and monitored on a regular basis.
b. An independent decision-making body, that includes a variety of disciplines, is essential. A courts based system is not suitable to for a flexible, accessible and individualised response. This body must have the human rights of the individual at its core.
c. A person who will have someone else make decisions for them ('facilitated decision-making') should have the right to challenge the decision.
d. Advocacy and other supports should be provided to ensure that the person is fully represented and can take part in the process.
e. A person should not be allowed to make an informal decision for someone else, outside the facilitated decision-making process. However, informal supports (e.g. asking others for advice) should be recognised as important and valid.
f. A facilitated decision-maker will only be appointed where the person's will and preference is not known and where supports have been attempted but have not led to a decision. However, supports should continue to be provided even after a facilitated decision-maker is appointed as this could augment the person's decision-making capability.