Article 12 of the United Nations Convention on the Rights of People with Disabilities (UNCRPD)

Research on Models of Supported Decision Making

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Introduction

This research was triggered by the ratification by Latvia of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) on 28 of January 2010. It joins the effort, both nationally and internationally, to understand the meaning of Article 12 UNCRPD (equal recognition before the law) and the best ways on how to implement it. In doing so it analyzes best examples of mental capacity legislation (the Mental Capacity Act 2005 of England and Wales), Canadian supported decision-making and capacity assessment legislation (Manitoba, British Colombia, Alberta and Ontario jurisdictions) and addresses the issues at stake in the development of mental health care advance directives with a focus on the examples of the United States, the United Kingdom and Scotland.

It was not the aim of the research to identify the best country example from the perspective of its full compliance with the provisions of Article 12 UNCRPD. Such a country does not exist, worldwide jurisdictions which have adopted supported decision-making legislation and policies are evolving and have imperfections. Moreover, the suitability of the experience of other countries to the Latvian context is open for debate and should be carefully addressed.

From this perspective the text below constitutes itself in an open-ended research which contains nonetheless valuable information for all the stakeholders interested in and responsible for the implementation of Article 12 of the United Nations Convention on the Rights of People with Disabilities.
Legislative and policy implications of article 12 of the UNCRPD

Article 12 (equal recognition before the law) of the UNCRPD recognizes people with disabilities as persons before the law and stipulates they shall have legal capacity on an equal basis with others. It provides for the right to seek support in the exercise of legal capacity and requires that safeguards be put in place both for measures that limit/ remove legal capacity or for abuse that might occur in a supported decision making mechanism. It also gives them the right to own and inherit property and not be arbitrarily deprived of it, the right to control one’s own financial affairs and have access to bank loans, mortgages and credit.  

Reformation of legislation and policy for compliance with article 12 will require adopting several measures: redefining capacity in accordance to current trends in modern legislation (I), providing for reasonable accommodation for exercising legal capacity (II), reforming the system of substitute decision-making (III) and making arrangements for a supported decision-making one (IV).

I

As the example of the United Kingdom capacity legislation shows the main elements of a progressive legislation will have to be: a presumption of capacity, a clear statement that capacity is decision-specific and a requirement that all alternatives that would help people with mental

2 “1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.  
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.  
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.  
4. 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.  
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.”
disabilities make their own decisions have been considered before incapacitation proceedings take place.\(^3\)

II

Reasonable accommodation for legal capacity represents a two direction process: one is to provide accommodation for autonomous decision making status\(^4\), the other to provide accommodation for supported decision-making status.\(^5\) The first step would be providing for accessible communication which is required by articles 9 (accessibility) and 21 (freedom of expression and opinion and freedom of information) of the Convention.\(^6\) It follows that all institutions in which people with disabilities could exercise legal capacity (doctor’s office, banks, notaries, courts, prison systems etc.) need to create and maintain quality services as a form of reasonable accommodation for legal capacity.

Systematic accessibility measures may be sufficient in some cases where people with disabilities meet the legal capacity test but many people will need personalized support systems which will fit their needs.\(^7\) To this aim article 12 provides the foundation for establishing a positive law which establishes an individual right to supported decision-making. Such legislation has to include an explanation of supported decision-making and outline the basic duties, obligations and rights of those providing and receiving support. Provisions need to be put in place that will make the whole process accountable which will allow the review of decisions and actions of

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\(^4\) In assisted decision-making a person has capacity to consider a decision and different options and weigh them up. In other words he/she can meet the legal capacity test.


\(^6\) Communication is defined in Article 21 as including “languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human reader and alternative modes, means and formats of communication, including accessible information and communication technology”.

\(^7\) A mental illness or learning disability can affect people’s ability to make decisions to a greater and lesser extent. Some people might be temporarily unable to take a decision during a period of acute illness such as mania. Some people might be able to take day-to-day decisions but might need help with more complex decisions. Other people might suffer from progressive dementia which will remove all the decision-making abilities.
those providing support. The situations which will mostly need formal accountability are: communicating and interpreting a person’s will and administration of financial resources.

The requirements of Article 12 read in conjunction with those of Article 2 are conducive to a test for reasonable accommodation for legal capacity. The elements of such a test have been outlined by Bach:

“Is a person able to make and communicate a certain decision on his/her own without support (functional test)?

If not, is the person able, with support, to meet the tests of mental capacity sufficient for him/her to be able to be recognized as a legally capable person for the purposes of a particular decision/action? If so, what type of support is necessary for this purpose?

Is the person able to demonstrate capacity (for contract, testimony, informed consent) sufficient to be recognized as a legally capable person with function specific-accommodation or are accommodations needed to manage a particular decision/act (interpreter, translator, augmentative communication device, communication assistance to other parties, decision-making assistance)?

If not, is the person able to engage representatives in a fiduciary relationship (supported decision-making network) to communicate and represent the individual’s personhood to others, based on their trusted relationship and personal knowledge of the person (accommodations for personhood/personal representation)?”

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8 Ms. Edah Wangechi Maina, *The right to equal recognition before the law, access to justice and supported decision-making*, CRPD Conference of Parties, 2-4 September 2009, New York.

9 Reasonable accommodation” means 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.

III

In the long run, the implementation of article 12 means the elimination of full guardianship and the establishment of a supported decision making system which will provide different alternatives to the different types of support people with disabilities need. Until the transition from one system to another is completed and if partial guardianship is adopted it can exist only under certain conditions. These should be: if the law applies to persons who do not object to having a guardian, if the law provides for guardianship only as interim measure and requires that supported decision-making be developed for each individual and if it will be repealed when there is a comprehensive program to ensure that decision-making support is provided to all those who need it.  

IV

Article 12 of the UNCRPD provides for the individual right to choose who will provide support. Around the world there are legal models where individuals do not have to demonstrate they meet the usual tests of legal capacity to make this decision-as long as they can demonstrate that they trust the people who will be their support network. This has to be registered in some way so that when third parties question a person’s capacity the network can confirm its status as a support to the person who maintains his/her legal capacity.

Some countries have begun to formally design and implement national programs of supported decision-making. These programs are evolving and have imperfections, but they all operate from a position that recognizes the centrality of the individual to her own life choices. Models of supported decision-making vary, taking many forms and ranging from 0% to 100% support, depending on the needs of the individuals in question. Most commonly supported decision-making models are: support networks, personal ombudspersons, community services, peer support, personal assistant or advance planning/directive.

Mental capacity legislation-England and Wales

There is a detectable trend in modern legislation, which will be emphasized in the examples set below to enshrine a powerful presumption of capacity and to insist that capacity is not a binary concept and that one person might be capable in one sphere and might need assistance in exercising that capacity in another (in other words that there are varying degrees of capacity and incapacity). This means that the first impulse of the State should be to intervene (under a principle of proportionality) to maintain capacity and assist people make their own decisions. Therefore, there should be a strong policy of assisting persons in their remaining decision-making capacities and enhancing them for as long as possible. In accordance with human rights standards, interventions should be with measures that are least restrictive on capacity and are proportionally tailored to the individual circumstances.

Section 1 of the Mental Capacity Act 2005 of England and Wales, entered into force on 2 April 2007 lays down five important principles: a person is presumed to have capacity unless proven otherwise; a person must be supported to make their own decisions and given all practicable help before being treated as not having the ability to make decisions; a person should not be treated as lacking capacity because they made un unwise decision or one that goes against societal norms; if a decision is made on behalf of a person lacking capacity it must be in their best interests; anything done in on behalf of a person with limited capacity should be the least restrictive of their basic rights and freedoms.

Therefore, according to the Mental Capacity Act 2005, capacity is decision-specific, meaning that it is assessed in relation to a person’s ability to make a particular decision. It is not assessed against their ability to make decisions in general. Loss of capacity can therefore be partial.

Capacity is also time specific, which means that it is assessed at the time that the decision needs to be made.
Even if a person lacks capacity in relation to a particular decision or type of decision, he/she should as far as reasonably practicable still be involved in the decision-making process. The decision-maker must take into account the person’s past and present wishes and beliefs and values that would be likely to influence him if he were making the decision (section 4(6) of the Act). The decision-maker must therefore make all reasonable efforts to discover whether the person has expressed relevant views.

Before a person is declared to be legally incapable, he must be given support to help him to make the decision. A person should not be considered unable to make a decision unless all practicable steps to help him to do so have been taken (section 1 (3)).

A person is considered not to be able to make a decision for himself if he cannot: understand the information that is relevant to the decision, even after an appropriate explanation has been given (3 (2)). The sort of information that would be “relevant” includes details about the nature of the decision, why it is needed and the likely consequences of deciding/not deciding.

Being able to retain the information for only a short period does not necessarily mean that a person is unable to make a decision, provided it is retained for long enough to make an effective decision. The length of time needed may vary according to the decision in question (3 (3)).

If a person is able to do all these things, he/she will still be unable to make a decision if he cannot communicate it, even after all practical help-speech therapy has been given. For this purpose-non-verbal communication is considered communication. A person is considered to be unable to communicate if unconscious of suffering from a condition which prevents them from speaking and moving (3 (1) (d)).

A person will lack capacity if he/she is unable to make a decision even after all practical support has been given to him. When assessing whether a person has capacity, the Court can consider how much help he needs to make the decision in question.

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12 Section 4(4) of the Act, “He must as far as reasonably practicable permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him”.
As emphasized above, the test of capacity is a test at law. The Queensland Law Reform Commission has noticed in 2008 that in the process of reforming the guardianship system it will be essential for those who asses capacity to understand the purpose, application and limitation of such assessments.  

The Mental Capacity Act 2005 [UK] requires the Lord Chancellor to prepare and issue numerous codes of practice, including a code of practice for the guidance of persons assessing whether a person has capacity in relation to a matter. A person who is acting under a specified role under the Act in relation to a person who lacks capacity is under a duty to have regard to the code.

In New South Wales, the Attorney General’s Department has in 2008 published a guide book for assessing capacity called Capacity Toolkit. It is meant to assist government employees, community workers, professionals and families in identifying weather the individual has decision-making capacity. It provides information and guidance about issues relating to capacity and capacity assessment.

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14 Section 42 (1) (a).
16 Section 42 (4).
Supported decision-making in Canada

Canada has been developing, even before the adoption of the United Nation Convention on the Rights of People with Disabilities, various formalized and semi-formalized supported decision-making arrangements. Such arrangements have been included into legislation and policy for over a decade now and bear different names: assisted decision-making, supported-decision making, co-decision-making, associate decision-making. They vary in accordance with the type of guardianship law of each Canadian province.

Key principles of the supported decision-making model in the Canadian law

By now it is generally considered that supported decision-making is one of the least restrictive/intrusive but most effective alternative to court-ordered guardianship.19

The basic assumption of the Canadian law is that each individual, regardless of the severity of disability has the ability to act if he/she is embedded within a network of persons whom he/she trusts. With the help of this network it is regarded as possible to determine the individual’s wishes and communicate them in a legal manner as his or her own decisions.

As will be exemplified below, there is a legislative recognition of the person’s right to self-determination, a presumption of capacity as well as the right to decision-making support.

One of the main innovations in the legislation is that persons with more significant disabilities can enter into representation agreements with a support network simply by demonstrating “trust” in the designated supporters. A person does not need to prove legal competency under the usual criteria, such as having a demonstrated capacity to understand relevant information,

appreciate consequences, act voluntarily and communicate a decision independently, in order to enter this agreement.

A number of individuals and support networks have entered representation agreements as an alternative to guardianship or other forms of substitute decision-making. This is the case of the Alberta and British Colombia (B.C) jurisdictions. In the latter jurisdiction a community-based Representation Agreement Resource Center assists in developing and sustaining support networks by providing information, publications, workshops and advice. The Center also oversees a registry in which a network can post an agreement for other parties to view if required before entering a contract with the individual.

A supported decision-making network is a group of people (family and friends) who know a person and make a commitment to provide assistance in making life plans and personal decisions. Assistance can mean interpretation, advocacy, information and consultation.

There is also a legislative recognition that a person’s expression of his or her will and intent is the basis of decision-making capacity and that personal decision-making is an interdependent process with others.

**Principles of the Manitoba supported decision-making legislation**

In the Manitoba “Vulnerable Persons living With a Mental Disability Act” assisted decision-making is specifically identified and defined as an alternative to court-ordered guardianship.

The Preamble of the Act is a restatement of the common law presumption of capacity and contains 4 principles which endorse supported decision-making: the importance of encouraging people to make their own decisions, the importance of a person’s support network for the purposes of assisting with decision making and enhancing the person’s independence, the
doctrine of the least restrictive and least intrusive form of intervention and the principle of using substitute decision-making as a last resort.  

Supported decision-making is referred to as “the process whereby a vulnerable person is enabled to make and communicate decisions with respect to personal care or his or her property and in which advice, support or assistance is provided to the vulnerable person by members of his or her support network”.  

As the definition implies assistance extends not only to the deliberation necessary for decision-making but also the communication of a decision that has been made by an adult. The Act further states that “supported decision making by a vulnerable person with members of his or her support network should be respected and recognized as an important means of enhancing the self-determination, independence and dignity of a vulnerable person.”

**British Colombia Supported Decision Making Agreements**

Canadian jurisdictions have become leaders in the legal implementation of supported decision-making model by the adoption of statutes permitting individuals with disabilities to create private agreements authorizing others to assist with decision making. The province of British Columbia in Canada is one of the leading jurisdictions in incorporating supported decision-making into law, policy and practice. An individual with disabilities can enter a “representation agreement” with a support network. The agreement is a sign to others, including doctors, financial institutions and service providers, that the individual has given the network the authority to assist him/her in making decisions and represent him/her in certain matters.

The Act states that “an adult may make a representation agreement (…) even though the adult is incapable of making a contract or managing his/her health care, personal care, legal matters,

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23 Section 6 (1) of the Act.

24 Section 6 (2) of the Act.

financial affairs, business or assets”. Therefore, an individual can enter a representation agreement despite an inability to demonstrate that he or she has legal capacity in the traditional sense. The Act does not require competency testing to enter agreements, but makes provision for more flexible standards of competence to make a decision.

In considering whether the person is incapable to enter a representation agreement the following factors need to be taken into account: whether the adult communicates a desire to have a representative make, help make or stop making decisions, whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others, whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult, whether the adult has a relationship with the representative that is characterized by trust.

Therefore, the state fully recognizes an individual’s legal capacity if either the individual can demonstrate to others his or her will or intent or if the individual personhood can be articulated by others who have sufficient knowledge of the individuals’ unique form of communication.

Under the British Colombia-Representation Agreement Act 1996 (RAA) an adult can enter a representation agreement with a trusted person (support network) who is empowered either to assist the individual with making or communicating the decision or to make decisions for him or her. Therefore, under the private representation agreement model of supported decision making, an individual who might not be able to demonstrate that he/she has legal capacity in the traditional sense may enter into an agreement with an individual or support network to provide her with assistance making or communicating decisions which will be legally binding.

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26 Section 8 of the Act.
27 Section 8 (2) (a) of the Act.
28 Section 8 (2) (b).
29 Section 8 (2) (c).
30 Section 8 (2) (d).
31 Section 7 of the Act.
The act provides for registration of such individuals or networks to secure their status in the decision-making process related to health care, financial or other decisions. The representation agreement can be entered into a special registry and the person with a disability can authorize registry access to third parties to view the agreement. Representation agreements have to also indicate a monitor of the representative. Any person can report irregularities and potential undue influence or abuse to the Public Guardian and Trustee who may conduct an investigation of the allegations.

The paradigm created by the RAA is predicated on a relationship of trust and creates a mechanism which resembles the powers of the attorney, though with a generous and flexible concept of the legal capacity required to enter into such an agreement. The Act requires that the representative consult with the principal to the extent reasonable to determine the principal’s current wishes.

As indicated above, representation agreements would be a form indicating who will be the representative/representatives (BC agreements stipulate that a person can have one or several representatives which are assigned a different area of authority or part of the same authority—thus the name of “support network”), who will be a monitor of the representatives and of the decision-making process as well as particular ways of communicating and expressing wishes.

Alberta’s Adult Guardianship and Trusteeship Act 2008

Another piece of Canadian legislation which offers various choices for adults who need assistance is the Alberta’s Adult Guardianship and Trusteeship Act 2008. Two of these choices shall be analyzed above: supported decision-making and co-decision-making orders.

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32 Section 9 (2) of the Act.
34 Section 12 of the Act.
35 Section 30 of the Act.
36 Section 16 (2) (a) of the Act.
37 http://www.canlii.org/en/ab/laws/stat/sa-2008-c-a-4.2/latest/sa-2008-c-a-4.2.html, in force since Oct. 30, 2009. The Act is build on the principles of: presumption of capacity until the contrary is determined ((2(a)); the manner of
Supported Decision Making

There is no court proceedings involved in a supported decision-making arrangement. The adult and the support person just need to sign a supported decision-making authorization (SMDA) form stating the purpose of the arrangement and the types of decisions covered. At any time, either the supported person or the supporter can end the supported-decision arrangement.

To enter such an authorization the adult needs to prove he “understands the nature and effect” of the arrangement. Only “personal”, non-financial legal matters can be covered. Decisions taken with the help of such an authorization are recognized as having been taken by the person (not the supporter) and the supporter bears no legal responsibility for the decisions taken this way. If there are “reasonable grounds” for suspecting “undue influence” it is lawful not recognize such decisions.

In a policy statement paper, the government of Alberta has suggested that the provision for supported decision-making was especially designed for people who have troubles in communicating decisions but whose capacity to make decision was not affected. Also, it has indicated that if the adult looses the capacity to make decisions and the Court appoints a co-decision maker or a guardian the supported decision-making authorization ends. However, to avoid the appointment of a guardian, persons with disabilities are advised to think about registering a Personal Directive which would come into effect if the capacity to make decisions was lost.

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38 http://www.seniors.alberta.ca/opg/Guardianship/Forms/opg5557.pdf
40 Section 4 (1) of the Act.
41 Section 6 and 10 of the Act.
42 http://www.seniors.alberta.ca/opg/Guardianship/Brochures/opg5609.pdf
Co-Decision-Making Orders (CDMO)

The Act allows for a co-decision making order to happen when an adult’s capacity to make decisions in certain areas is significantly impaired and only if the adult has agreed to the order. Even then, it can only happen after less intrusive and less restrictive measures have been considered and implemented and have proved not to be effective to meet the adult’s needs. Where co-decision makers cannot agree it is implied that the assisted person’s views prevail. Co-decision maker orders can end with a simple withdrawal of consent.

The application before the court for a co-decision-making order has to include a number of forms including a capacity assessment form and the report of a review officer from the Office of the Public Guardian. Such an officer has the duty to visit the adult and inform him about the application and about the right to request a hearing.

If there is evidence that the adult has made a personal advance directive that is valid the Court “might not make a co-decision making order” and will rule on whether the appointment of a co-decision maker would be likely to produce benefits for the adult that would outweigh any adverse consequences for the adult.

The Court “shall specify a date in the order by which an application for a review of the order must be made, if the capacity assessment report indicates that the assisted adult’s capacity is likely to improve” and “may specify a date in the order by which the application for a review of the order must be made, in any other case”.

A co-decision maker is accountable to the Court for decisions made with the assisted adult. Anyone, including the assisted adult may ask the Court to review the co-decision making order at

44 Section 13 (4) (a) of the Act.
45 Section 13 (4) (c) of the Act.
46 Section 13 (4) (a) of the Act.
47 Section 17 (8)-(9) of the Act.
48 Section 13 (4) (2) of the Act.
49 Section 5 (b) of the Act.
51 Section 5 (g) of the Act.
52 Section 17 (8) of the Act.
any time. The Court will assess the adult’s needs as well as the decisions the co-decision maker and adult have made together. The Capacity Assessment Report will be reviewed, completed less than six months before the review, to determine if a co-decision arrangement meets the adults’ needs.

Co-decision making legislation also exists in the provinces of Saskatchewan, Manitoba and Yukon. Such types of legislations provide a legal framework for the informal support given during a decision-making process. All co-decision making provisions stipulate that the co-decision maker shares legal authority with the adult, that he/she should act in a manner that protects the adult’s civil and socio-economic rights and in preserving the adult’s capacity he/she should be encouraged to participate in the decision-making process to the fullest extent possible.

**Principles of Capacity Assessment**

Under the Act capacity is defined as “the ability to understand information relevant to a decision and to appreciate the reasonably foreseeable consequences of (i) making a decision or (ii) the failure to make a decision”.

The following apply to capacity assessments: a capacity assessment may be conducted only if the need for capacity assessments has been established (there must be legitimate reasons for a capacity assessment), an adult has the right to have assistance of an interpreter or the use of a device to assist the adult to communicate in order for the adult to be able to fully demonstrate his

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53 Section 21 (1) of the Act.
55 The Vulnerable Persons Living with a Disability Act, S.M. 1993, c. 29, s. 9 http://www.canlii.org/en/mb/laws/stat/ccsm-c-v90/latest/ccsm-c-v90.html
57 Section 21 (1) of the Act.
58 Section 1 (d) of the Act.
59 Section 3 (1) (a) of the Act.
or her capacity during the capacity assessment, an adult shall be given the opportunity to undergo a capacity assessment at a time when and under circumstances in which the adult will be likely to be able to demonstrate the adult’s full capacity. The Ministry may establish guidelines for the conduct of capacity assessments.

A capacity assessor may conduct a capacity assessment only if the adult has not refused to undergo or continue with the capacity assessment and in the opinion of the capacity assessor the adult understands the purpose of the capacity assessment and that the adult has a right to refuse to undergo or continue with the capacity assessment, is capable to consent to the capacity assessment, has consented to the capacity assessment.

The adult’s capacity to make decisions is taken by a physician, psychologist or other health care professional specifically trained to be a capacity assessor. The Ministry is under the obligation to establish and approve a training course for capacity assessors. Therefore, the scope of the capacity assessors is expanded beyond the clinical judgment to include a person designated by law as qualified to do the assessment of capacity.

A universal tool or technique of assessing capacity does not exist because it could not apply to a broad range of circumstances. Best practices of capacity assessment are rather based on an agreed set of principles surrounding assessment and an agreed definition of capacity. Such is the case of Ontario, Canada whose Capacity Assessment Office has issued capacity assessment guidelines with a focus on: the right to self-determination, presumption of capacity and guardianship as a last resort.

The Capacity Assessment Office runs under the Ministry of the Attorney General and trains health professionals to become capacity assessors in accordance with the Ontario Substitute Act.

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60 Section 3 (1) (d) of the Act.
61 Section 3 (1) (e) of the Act.
62 Section 3 (2) of the Act.
63 Section 3 (a) of the Act.
64 Section 6 also refers to registered nurses, registered psychiatric and mental deficiency nurses, occupational therapists and social workers.
65 Section 8 of the Act.
Doctors, registered nurses, psychologists, registered social workers and occupational therapists are eligible to become capacity assessors as long as they complete training and undergo at least 5 assessments in 2 years while continuously participating in education activities provided by the Assessment Office. The institution is also responsible for making available to the public a list of qualified assessors and for operating a Financial Assistance Plan to help individuals who request an assessment but cannot afford to pay for it.

According to the Alberta and Ontario legislative models all states should adopt capacity assessment acts outlining a new process by which functional assessment of capacity should take place. The tools used should be based on certain principles which accommodate the individual circumstances and are applied consistently by those designated as qualified assessors. The principles guiding the assessment process should take into consideration that capacity can fluctuate, that assessment should be specific to the areas of decision-making needed to be made and that the manner of communication does not affect the decision-making ability of a person. These types of legislation move capacity assessment beyond a clinical judgment to one which is more inclusive and procedural and therefore more accountable.

During a conference which took place in Riga, Latvia between 23-25 March 2011 Professor Robert Gordon, Canadian academician and disability law expert, gave a presentation on the best practice principles in assessing incapability in Canada. The primary assumptions of any incapability assessment must be that incapability is decision specific, can vary over time/ fluctuate and may be a function of lack of support. Different constituencies of disabled people require different assessment techniques and a collaborative, multi-disciplinary team approach to assessment should be preferred.

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68 http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/capacityoffice.asp
69 During a conference which took place in Riga, Latvia during 23-25 March 2011 Professor Robert Gordon, Canadian academician and disability law expert, gave a presentation on the best practice in assessing incapability in Canada.
70 The text is a mere reproduction of his PowerPoint presentation.
Legislation dealing with capacity assessment standards should include: the principle of presumption of capacity until proven otherwise (which means that the issue at stake should be assessing incapability and not capability), statutory tests of determining incapability as well as provide for assessment procedures.

Incapacity assessments should not take place if there are other alternate ways to adequately meet the adults’ needs and they will be carried out only if they will serve the interests of the adult. An adult has to have the right to be informed of the intention to conduct an incapability assessment and to be informed of its outcome.

An incapability assessment is a process, completed in consultation with the adult and those who are supportive of the adult. They are concerned only with the adult’s ability to make and carry out decisions that need to be made at a certain point in time. The assessment needs to be carried out by qualified assessors (regardless of profession), education and training being required for qualification. There needs to be a professional regulatory body (professional college) who helps determine standards.
Advance directives and advance statements

Advance directives give persons with recognized autonomous decision-making the power to designate someone to make decisions on their behalf at a point in the future when they might no longer be considered competent enough to enter agreements with others. These mechanisms place a person under substituted decision-making but only within the parameters established by the person. The term “advance directive” is generically used worldwide to denote a preference statement. In the United States of America it generally refers to a legally binding document which can nonetheless be overridden under certain specified by law circumstances. The Scottish and English legislations use the term “advance statement” to suggest that these documents are not legally binding but can more broadly be integrated into a plan of treatment agreed with clinicians. This collaboration can sometimes be regarded as limiting the patient’s autonomy, as opposed to advance directives whose filling in forms do not have to take into account the clinician point of view and therefore be considered to embody autonomy more. Both types of documents have in common the aim of increasing patient autonomy with respect to mental health care and reduce coercion into treatment.

In the United States of America, the Patient Self Determination Act gives people the right to make advance directives. The term refers to a legal document with statutory authority that individuals can use in future periods of incapacitation to plan their health care. According to the Act all health care facilitates receiving federal funds have the obligation to notify patients about this right as they enter the health system and adopt written policies for the implementation.

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71 Michael Bach, *Supported decision-making under article 12 of the UN Convention on the Rights of Persons with Disabilities, Questions and Challenges*, Notes for Presentation to Conference on Legal Capacity and Supported Decision-Making, Parents’ Committee of Inclusion Ireland, Athlone, Ireland, November 3, 2007, Canadian Association for Community Living, slide 5. The author however makes the point that this option is generally not available to people with severe intellectual and psychosocial disabilities because they are considered not legally competent to designate these authorities.


73 It can either be a living will or a durable power of the attorney for health care as long as it is recognized under law (statutory or as recognized by courts), section 4751 (4) of the Federal Patient Self Determination Act 1990, 42 U.S.C 1395.
of advance directives. It also stipulates that health care professionals as well as the community need to be educated on issues related to advance directives.

Ever since the adoption of the Act psychiatric advance directive statutes have been enacted by 25 U.S states. Although their content differs from state to state, they all include a checklist form meant to help consumers prepare them. It addresses information about medication and specific treatment they would like to receive although in practice advance directives are used more for anticipatory refusal of medical treatment. The document needs to be signed by two witnesses and to specify the name of a person that should be contacted in case of an emergency.

The U.S advance directives reflect the consumer choice model in health care and are considered to embody patient autonomy because people can seek the help of third parties when producing these documents, without involvement of mental health care providers. It is also very important that for the purposes of making them, determination of competency is not formally carried out. The statement of a witness or a notary that the person appears of sound mind will suffice. The advance directive must be part of the medical record and it is legally binding in relation to mental health professionals unless physicians consider that they conflict with medical practice standards or emergency care or if the patient meets involuntary commitment criteria. Although an advance directive can be overridden, as a legal document it stipulates the circumstances when this may happen and legal action can be taken if this is felt by the patient to be unjustified.

In 2003, in the decision of Hargrave v. Vermont, the U.S Court of Appeals struck down the Vermont state law which allowed mental health care professionals to override patients’ advance refusal of medication through a care proxy. The plaintiff, who suffered from paranoid schizophrenia, claimed that she was being discriminated against because of her mental illness and excluded from a “service” (the durable power of attorney she had completed) as defined by the Americans with Disabilities Act. Following this decision, mental health care professionals

74 Ibid, section 1903 (m) (1) (A).
75 Ibid, section 4751 (E).
77 Ibid, p. 5.
78 Section 4751 (3) of the Federal Patient Self Determination Act 1990, 42 U.S.C 1395.
were forbidden to forcibly treat with medication, if medication was refused in a competently prepared advance directive.

In England and Wales advance statements have been recognized under common law and their place defined in the Mental Capacity Act 2005. 81 Section 4 (6) of the Act provides that when determining the best interests of a person who lacks capacity, any written statement made when they had capacity should be considered. However, it has been made clear that in the case of mental disorders, mental health legislation (Mental Health Act 1983) takes precedence over any provisions in the Mental Capacity Act 82. This clearly discriminates against people with mental disorders who should have the same rights as people with physical disorders where observance of their advance statements is concerned, unless in exceptional circumstances such as the likelihood of causing imminent and serious harms to themselves and others. But although advance statements can be overridden, the Act does provide for legal support for autonomy and self-determination in deciding the type of care and treatment patients would like to receive. 83

The best European example of a country that has adopted advance statements is Scotland. The Parliament has included advance statements in the mental health legislation- the Mental Health (Care and Treatment Scotland) Act 2003 (hereinafter the MHCT Act). 84

The Act defines an advance statement as a written statement, drawn up and signed when the person is well, which sets out how she or he would prefer to be treated or not treated if she/ he were to become mentally ill in the future. 85 In order to be valid, an advance statement must meet the following criteria: at the time of making the advance statement, the person must have the capacity of properly intending the wishes specified in it 86, it must be in writing 87, it must be

82 For example, a directive which refuses treatment will be ineffective if at the time when it was made the patient did not appreciate the implications of refusing treatment and can also be revoked if the patient has the necessary capacity to do so. 83 Since 1999 there has been a process aimed at reforming the Mental Health Act culminating in the passing of the Mental Health Bill 2006 to Amend the 1983. There was much support for a definition of impaired decision-making and for the provision of advance statements to be invoked during a period of impaired decision-making in the new legislation. This was repeatedly rejected by the government, concern about public protection out weight concerns about patient autonomy; advance statements have taken a clinical form.
86 Section 275 (2) (a)).
signed by the person making it and the person’s signature of the statement must be witnessed by someone who certifies in writing that in his opinion the person making the statement has the capacity to do so. Also, an advance statement may be withdrawn by the person who made it if at the time of making it the person has the capacity properly to intend to withdraw the statement.

It must be made in written form, signed and witnessed in the same way as the original statement.

In 2005 the Scottish Executive published a document called “The New Mental Health Act: A Guide to Advance Statements” which contains guidelines regarding how the advance directives should work in practice. This document is written for the patients and addresses their needs. For example, it is indicated that “in an advance statement you can say which treatments work well for you and which ones you would not want. You can give your views about medications, therapies or electro-convulsive therapy (ECT). It might be helpful if you could include any reasons for your views”. Furthermore, it states that “if a decision is made which goes against your advance statement you will be given the reasons in writing, a copy will be given to your named person, welfare attorney and your guardian and to the Mental Welfare Commission”. Also that “the person who witnesses your advance statement is confirming that in their opinion you are able to understand what you have written in the statement and the effect it might have on your future treatment. The witness does not have to be involved in writing the statement, nor do they have to agree with your wishes.” The witness can be either a clinical psychologist, medical practitioner, therapist, registered nurse, social worker or solicitor.

The Act imposes a legal obligation upon the Mental Health Tribunal and the medical practitioner treating the person to have regard to the wishes specified in the advance statement.

87 Section (275 (2) (b)).
88 Section (275 (2) (c)).
89 Section 275 (2) (d, e)).
90 Section 275 (c) (a)).
91 Section (275 (c) (b)).
94 Ibid., p. 6.
95 Ibid., p.8.
97 Section 276 (1) and 276 (3) (b, c) of the. Mental Health (Care and Treatment Scotland) Act 2003.
Treatment may be given that conflicts with the wishes expressed in the statement but if this occurs the responsible clinician must record in writing the circumstances and reasons why a certain treatment was authorized and the reasons why. He also has to supply the person who made the statement, that person’s named person, that person’s welfare attorney, that person’s guardian and the Mental Welfare Commission with a copy of that record. A copy of that record needs to be placed with that person’s medical records.

Along with guidance on how they can be constructed, the Guide also includes a sample of how advance statements should look like, as well as a sample of a withdrawal of advance statements.

Some considerations when developing advance directives

The idea behind the legally binding advance directives, as the case of the United States shows is that they cannot be easily over-ruled by mental health law. This means that the power of the psychiatrist will have legal restrictions. On the other hand, a jointly negotiated advance directive can also change the psychiatrist-patient relationship and be more effective by increasing the power of the latter through information and communication. It has been proven that when it comes to implementing advance directives, psychiatrists are not interested in the issue either because they do not know the law or they were not included in the process. It is very important to clarify the purpose of the psychiatric advance directive from the beginning. Research has shown that the success of such directives will depend on an understanding of what they are expected to do. The outcome will differ greatly in accordance with whether it is seen as a tool to promote autonomy or rather foster cooperation and communication.

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98 Section (276 (8) (a)).
99 Section (276 (8) (b)).
100 Section (276 (8) (c)).
102 Ibid., p. 176.
103 Ibid., p. 466.
104 Ibid., p. 130.
Therefore, when an advance directive is made three dimensions need to be taken into account: its legal status, whether it is independently or collaboratively made and what interventions it might cover.

Research shows that the interest of staff in advance directives is crucial and it is associated with the interest the patient has in making an advance directive. Unless support exists, people will not make them. This means that educating the staff is as much important as educating the patients. There is some suggestion that the low uptake of advance statements in Scotland is because no professional group has a duty or responsibility under the Act to introduce them to patients.

When storing an advance directive, the main criteria should be that it should be immediately and easily available to the treating doctor (for example at the front of the patient’s medical record, easily found by staff). In Scotland, the Mental Health Officer has a duty to inquire, at the time of assessment for detention/ compulsory treatment whether the patient has an advance statement. Therefore, there is a requirement that anyone treating the patient under the Act to take an advance statement into account. This includes not only the patient’s treating doctor but also the mental health tribunal where the patient is being assessed for compulsory treatment.

Latvia is currently under the legal obligation to take into account advance statements if a patient is not able to express his or her wishes at the time the medical interventions are made as required by Article 9 of the European Convention on the Human Rights and Biomedicine. Recognition in the national law of advance statements and/or advance directives is moreover a part in the implementation of article 12 of the United Nations Convention on the Rights of Persons with

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106 Mental Health Foundation researchers have reported that service users are discouraged from preparing advance statements with the patient because they are aware that they are not followed if they are sectioned (Mental Health Foundation 2005, Advance Statements in Mental Health Practice –Lessons from Bradford).

107 Ibid., p. 157.

108 Ibid., p. 137.

109 Ibid., p. 147.

Disabilities related to the exercise of legal capacity. Where health care is concerned an advance statement/directive would give persons with mental disabilities control over their treatment when they are incapacitated.

If they are recognized in law advance directives will have the necessary formality to be viewed as proper statements of a patient’s capable wishes and taken into consideration by mental health care professionals as part of their daily routine. An obligation to discuss advance statements with the patients would bring legislation in line with the principle of patient choice and involvement.

Research shows that advance directives can help improve the relationships between patients and clinicians, ensuring that communication is enhanced and that there is more appropriate sharing of ideas and the making realistic choices, whether to preferred treatment or to the options and consequences of reduced treatment. Evidence also points to the fact that advance directives have the potential to reduce coercive treatment, lead to discussions between consumers and clinicians that enhance their therapeutic relationship, provide emergency room and inpatient clinicians with valuable information about what has or has not worked for a consumer before and what treatment they will accept.

The question of whether psychiatric advance directives are a legal or a clinical judgment as well as the issue of the relationship between advance directives and mental health law will be crucial when drafting legislation and policy. Ideally, an advance directive to refuse medical treatment for mental disorder should be legally binding on the mental health care professionals in situations where it is clear they were intended to apply regardless of the fact that the patient is subject to compulsory powers under mental health legislation. Since in practice clinical judgment prevails a midpoint between being automatically bound by an advance directive and consulting it needs to be found. For this, safeguards need to be enshrined in law. Following the example of Scotland,

111 Latvia has ratified the UN CRPD on 28 of January 2010.
112 Ibid., p. 187.
114 Ibid. 40.
mental health care professionals should be required to record in writing the reasons for overriding an advance directive.