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Editorial

Dear Readers,

Welcome to the new version of INCLUDE. In 2007, our work was strengthened by an important new document: the United Nations Convention on the Rights of People with Disabilities. The Convention declared that all people with disabilities have full legal capacity to hold and exercise their rights. In this issue of INCLUDE, we have chosen some examples of legal capacity legislation from different countries in Europe and overseas.

Bienvenus dans la nouvelle version d'INCLUDE. En 2007, notre travail s'est renforcé d'un nouveau document important: La Convention des Nations Unies sur les Droits des Personnes Handicapées. La Convention déclare que toutes les personnes handicapées ont la pleine capacité juridique de conserver et exercer leurs droits. Dans ce numéro d'INCLUDE, nous avons sélectionné quelques exemples de législation sur la capacité juridique de différents pays en Europe et outre-mer.

IT IS MY PLEASURE to introduce to you the new edition of INCLUDE. The new look of our newsletter reflects new ways and ideas in delivering information and policy messages to our members and other target groups. However, Inclusion Europe continues to be committed to promoting the values of respect, solidarity and inclusion for people with intellectual disabilities and stands up for their rights.

In 2007, our work was strengthened by an important new tool: the UN Convention on the Rights of People with Disabilities. The ratification of the Convention and the implementation of its principles into national laws will be an exciting process. We will see our efforts turning into reality.

For people with intellectual disabilities, one of the most important issues in the UN Convention are the new principles regarding legal capacity. The Convention declares that all people with disabilities have full legal capacity to hold and to exercise their rights. Further, they have the right to receive the support in decision-making that they need.

Whether or not people have full citizen rights has a great impact on their lives. Traditionally, people with disabilities were often considered as not being equal to

others before the law. People with intellectual disabilities were thought to be incapable of deciding for themselves, of being educated, or of having a life equal to others. Today, it is a human rights issue to recognize all people as equals before the law.

In this issue, we have chosen some examples of legal capacity legislation in different countries in Europe and overseas. We also include once more the Conclusions of the Europe in Action 2007 conference in Warsaw on this topic.



Dorothee Reumann and Ingrid Körner

Let us enjoy the door opened by the UN Convention and work together towards the implementation of these changes in all European countries.



Ingrid Körner
President of
Inclusion Europe

Wir präsentieren Ihnen die neue Version von INCLUDE. Im Jahr 2007 wurde unsere Arbeit durch ein neues wichtiges Dokument gestärkt: das Abkommen der Vereinten Nationen über die Rechte der Menschen mit geistigen Behinderungen. Das Abkommen sagt, dass alle Menschen mit Behinderungen die volle rechtliche Befugnis haben, ihre Rechte einzufordern und auszuüben. In dieser Ausgabe von INCLUDE zeigen wir einige Beispiele für die rechtliche Befugnis in verschiedenen europäischen Ländern und anderswo. ★

Advancing Self-Determination of Persons with Intellectual Disabilities:

Overview of the Supported Decision-Making Model and Legal Provisions in Canada

Michael Bach

Canadian Association for Community Living



Michael Bach at the Europe in Action 2007

In many countries, people have the right to make their own decisions. They have this right because they understand what they are being asked to make a decision about. Unfortunately, in some countries, people with intellectual disabilities do not have this right to decide. Often, they are put under guardianship. This means that somebody else decides for them. We need to propose new models that allow people with intellectual disabilities to make their own decisions, while understanding that they might also need help to do this. We must find a solution that ensures the rights of people with intellectual disabilities but also gives them the support they need.

Dans beaucoup de pays, les gens ont le droit de prendre des décisions par eux-mêmes. Ils ont ce droit car ils comprennent les décisions qu'ils prennent. Malheureusement, dans beaucoup de pays, les personnes handicapées mentales n'ont pas ce droit. Très souvent, elles sont placées sous tutelle. Cela signifie que quelqu'un d'autre pourra décider pour elles. Nous devons proposer de nouveaux modèles dans lesquels les personnes handicapées mentales ont le droit de décider par elles-mêmes. Néanmoins, elles

peuvent aussi avoir besoin d'aide pour décider. Il faut donc trouver une solution pour garder les droits de la personne handicapée mentale tout en lui donnant en même temps le soutien dont elle a besoin.

In vielen Ländern haben Menschen das Recht, ihre eigenen Entscheidungen zu fällen. Sie haben dieses Recht, weil sie verstehen, worüber sie aufgefordert sind, Entscheidungen zu treffen. Leider ist es so, dass in manchen Ländern Menschen mit geistiger Behinderung dieses Recht nicht haben. Oft haben sie einen Vormund. Das bedeutet, dass jemand anderes für sie die Entscheidungen fällt. Wir müssen neue Modelle vorschlagen, die Menschen mit geistiger Behinderung ermöglichen, eigene Entscheidungen zu fällen. Dabei müssen wir verstehen, dass sie dabei manchmal Hilfe brauchen. Wir brauchen Lösungen, die Menschen mit geistiger Behinderung ihre Rechte lässt und gleichzeitig auch die Unterstützung gibt, die sie brauchen. ★

Introduction

MOST COUNTRIES HAVE SOME LEGAL PROVISIONS that provide people the right to self-determination – to make their own decisions about their health care, personal care, and property/financial decisions. These legal frameworks usually rest on the assumption that self-determining adults must be fully capable of understanding all of the nature and

consequences of decisions they make: whether it is giving informed consent for surgery; entering a contract or taking out a bank loan; or entering an agreement for home care services. The legal frameworks usually provide some means for determining how to make decisions for those whose capacity to meet this standard is questioned by a physician, or banker or landlord or other party with whom a person wishes to contract. These alternative means are often referred to as guardianship or substitute decision-making powers.

In effect, they remove the legal person from the individual and give it to another body (a public trustee) or another person to make decisions on behalf of the individual whose personhood has been removed.

People with intellectual disabilities and their advocacy organizations are now questioning this set of legal institutions. At their founding Conference in 1991, the first resolution adopted by the membership of People First of Canada was a call to end guardianship because of its violation of the rights to self-determination. Along with People First of Canada, the membership of the Canadian Association for Community Living believes that guardianship represents removal of fundamental rights and discrimination on the basis of disability. Yet we also recognize that people often need assistance to make their own decisions. Our usual approaches to decision-making have not provided a solution to those who want to maintain their legal personhood, but who also want and require assistance to make personal decisions.

To define an alternative to guardianship and substitute decision-making provisions – one that does not remove a person's right to make decisions but recognizes the need for assistance in decision-making – is a challenging task. It requires re-thinking the nature of personhood, decision-making, and competence, as these have come to be defined legally, scientifically, and ethically. A number of models of decision-making have developed in recent years that are presented as alternatives to guardianship, and as remedies to some of the limitations of the institution of guardianship. Powers of attorney, mentors or 'legal friends,' or surrogate decision making for particular decisions are examples. However, these approaches do not challenge the distinction between the competent and incompetent on which an individual's personhood can be legally removed.

Model of Supported Decision Making

A MODEL OF SUPPORTED DECISION-MAKING has been developed in the Canadian legal context that goes much further than other alternatives to guardianship in protecting the right to self-determination. This approach recognizes that individuals often require assistance in making decisions; that it is the decision-making process that is competent or incompetent, rather than the individual him or herself; and that individuals are interdependent beings, not isolated, independent selves.

The approach has been developed through a number of consultations in different jurisdictions in Canada, led by the Canadian and provincial/territorial Associations for Community Living. The model has a few key elements:

First, supported decision making is based on a set of guiding principles that emphasize the persons' right to self-determination and autonomy, the presumption of capacity, and the right to decision-making supports.

Second, a supported or interdependent decision-making approach makes available to individuals a range of decision-making supports to assist in decision-making, without legally removing decision-making rights from individuals. A supported decision-making network is a key component of such a model. It is a group of people, usually family and friends, who know a person and make a commitment to provide assistance in making life plans and personal decisions. Their decision-making assistance can take many forms from interpretation, to advocacy, to information, and consultation.

A third feature of a supported decision-making approach is an understanding 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 more an interdependent process with others, than an independent one done all by oneself.

Fourth, supported decision making is based on the expression of trust. It is on the basis of an expression of 'trust' that some individuals will appoint or designate decision-making supporters. By virtue of the conventional criterion, many individuals with intellectual disabilities would be unable to appoint decision-making supporters because they would not be considered to have the capacity to do so. Thus, a vicious circle would be established. Individuals would not be able to enter agreements that acknowledge the role of supporters in decision making without meeting a capacity test, but in not meeting the capacity test they would be denied decision-making support and thereby would be made subject to guardianship.

A fifth feature of supported decision making would be a new system of accountabilities to make supported decision making effective, and consistent with the principles of self-determination and presumption of capacity. In order for a supported decision-making model to be effectively implemented a number of accountabilities have been proposed:

- accountability of personal network (supporters in decision making), the state, administrators or other agents, service providers including physicians and other professionals, and planning support agents to a person's individual plan, authored, co-authored, or approved by that person;
- accountability of the supporters in decision-making to carry out their duties consistent with the trust vested in them, and in ways which respect the person's will and intent. Mechanisms to challenge the appointment or designation of supporters would thus need to be established, and all decisions would need to be challengeable on the basis that adequate support was not provided, that the decisions expressed did not respect the person's will and intent, or that substitute rather than supported decision making was being exercised by the supporters.
- a mechanism for designating and acknowledging a particular individual or group of individuals as support decision makers
- accountability of the state to make all reasonable efforts to: establish a personal network for individuals who are in

need of supported decision making, given the importance of such a network in enabling individuals to exercise their right to self-determination; provide support to individuals and support networks in mediating conflicts in decision making; and to provide educational and information resources to individuals and support networks in managing a supported decision-making relationship;

- accountability of physicians and other third parties to a supported decision-making process, where:
 - the criteria of competent decision making are clearly spelled out
 - will and intent are identified as an adequate basis for making decisions
 - the role of the support network is recognized
 - "trust" is established as the key criterion for designating support decision makers
 - a means is established for physicians or other third parties to document the process for obtaining consent to treatment or to enter another kind of agreement or contract.

Legislative provisions in Canada enabling supported decision making

NO COMPREHENSIVE LEGISLATIVE AGENDA of this nature is in place in Canada. However, there are a few legislative provisions worth noting that recognize a supported decision-making approach.

Under the British Columbia *Representation Agreement Act* people can enter into an agreement with a person or a group of persons (e.g. a supported decision-making network) to assist in making decisions. 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 agreements enable a person to voluntarily select and empower one or more individuals to assist, support, act or make decisions on his or her behalf when s/he is no longer considered capable of making decisions independently. The agreement can be written to specify the conditions under which representatives' substitute decision-making authority will come into effect, and the nature of assistance that will be provided. In order to enter representation agreements adults must be considered capable of providing consent – that is understanding the nature, purpose, and consequences of the agreement they are entering. However, the statutory provisions do not require competency testing to enter representation agreements. The Act makes provision for more flexible standards of competence than those usually found – including communicating a desire to have a representative assist in decision making, demonstrating choice that expresses approval or disapproval of others, awareness of the role of the representative(s), a trusting relationship with the representative.

These provisions are one area in law where interdependent personal relationships involving a person with a disability

are recognized, and in a manner which promotes the legal right of self-determination of a person (by creating more flexible standards for competency to make a decision, and by acknowledging that the defining feature of the relationship is one of trust rather than simply caregiving or dependence). Representation agreements are a mechanism for granting authority similar to that of powers of attorney. The key difference is that they allow for a range of decision-making assistance, short of substitute decision making.

In Manitoba, the *Vulnerable Persons Living with a Mental Disability Act* recognizes in s.6 "supported decision making" as a means of "enhancing the self-determination, independence, and dignity of a vulnerable person" – which by the statutory definition includes an adult with a disability. The Act provides for an individual to take advantage of a "support network" in providing assistance to make personal care or property decisions, thus limiting the need to resort to substitute decision-making arrangements. Provincial policy is being implemented to provide back-up support and assistance for the development and sustaining of personal support networks given the growing understanding of the challenges such networks face. The legislation recognizes that persons often make decisions with the support of others, and the legislation affirms that persons should have the legal right to do so. However, the legal framework does not provide any legislative protection to those whose competence to make a particular decision on their own, independently and autonomously, is questioned by a third party – a physician, or a banker, etc. This questioning can trigger a competency determination, and provisions for substitute decision-making are available for those determined incompetent to make decisions on their own.

In the Saskatchewan *Dependent Adults Act* and in the Ontario *Substitute Decision Making Act*, a finding of incapacity does not necessarily require that the court appoint a guardian. The Ontario Act stipulates that upon a finding of incapacity, viable but more informal means for making decisions than substitute decision making may be recognized. However, the legislation does not make explicit what these means might be, or whether supported decision-making arrangements



Europe in Action 2007, Warsaw, Poland

would suffice. Similarly, the Saskatchewan Act does provide that upon a finding of incapacity the court does not necessarily have to appoint a guardian; other arrangements can be made. The Northwest Territories *Guardianship and Trusteeship Act* does make provision for a test of capability in decision making that recognizes the role of assistance. In s. 12(1) a person is considered "capable" if the person has

(a) the ability, by himself or herself or with assistance, to understand information that is relevant to making a decision concerning his or her own health care, nutrition, shelter, clothing hygiene or safety; and

(b) the ability, by himself or herself or with assistance, to appreciate the reasonably foreseeable consequences of a decision referred to in paragraph (a) or lack of such a decision [emphasis is in the text of the statute].

In both the Northwest Territories and Ontario jurisdictions, supported decision-making is to be taken into account prior to an application being made for guardianship or upon

review of a guardianship order. But once the application is made, individuals are to be submitted to competency tests by competency/capacity review boards.

Outstanding Questions

THE MODEL OF SUPPORTED DECISION-MAKING outlined above goes some way in re-drawing the usual boundary between the competent and incompetent. A more fundamental re-thinking of personhood is still needed to challenge the assumption that persons can be reduced to decision-making capacity, even with assistance. Alternative approaches to defining persons that are rooted in a narrative approach to bioethics provide promising new directions for securing the right to self-determination and addressing the emerging limitations with the supported decision making model. These new directions will be explored in my presentation at the Inclusion Europe conference in Warsaw. ★

Legal capacity, guardianship and supported Decision-Making: The situation in Hungary

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There are two systems of guardianship in Hungary: plenary and partial. When people are placed under plenary guardianship, they cannot vote and they cannot sign job contracts. Most people with intellectual disabilities are put under plenary guardianship. This is not good, but even worse is the fact that the number of people under guardianship has nearly doubled between 2001 and 2004. However, there are also some good things. The Hungarian Parliament adopted a new resolution which introduces the concept of supported decision-making into the law. This will hopefully change the Hungarian guardianship legislation in the future.

Il y a deux systèmes de tutelle en Hongrie: tutelle complète ou tutelle partielle. Quand des gens sont placés sous tutelle complète, ils ne peuvent plus voter et ils ne peuvent plus signer de contrat. La plupart des personnes handicapées mentales sont placées sous tutelle complète. Ce n'est pas une bonne chose. Mais il y a quelque chose de pire encore: le nombre de personnes placées sous tutelle a doublé entre 2001 et 2004. Néanmoins, il y a aussi certaines choses positives. Par exemple, le Parlement Hongrois a adopté une nouvelle résolution. Ce nouveau texte inclut le concept de soutien à la prise de décision dans la loi. Ceci, espérons-le, va peut-être changer la législation hongroise sur la tutelle dans le futur.

Es gibt zwei Systeme der Vormundschaft in Ungarn: die volle Vormundschaft und die teilweise Vormundschaft. Wenn Menschen unter volle Vormundschaft gestellt werden, dürfen sie nicht wählen. Sie dürfen keinen Arbeitsvertrag unterschreiben. Die meisten Menschen mit geistigen Behinderungen stehen unter voller Vormundschaft. Das ist nicht gut. Noch schlechter ist jedoch, dass sich die Zahl der Menschen unter voller Vormundschaft zwischen 2001 und 2004 verdoppelt hat. Es gibt jedoch auch gute Dinge: Das ungarische Parlament hat beschlossen, das Konzept für ein unterstütztes Entscheidungstreffen zu einem Gesetz zu machen. Dies wird hoffentlich die ungarische Gesetzgebung zu Vormundschaften in Zukunft verändern.

ÉFOÉSZ was established 25 years ago as an umbrella body for organizations concerned with the care and rehabilitation of people with intellectual disability in Hungary. At the present time our organization represents 50 member associations, 26 local branches and 22.000 individual members all over the country and we run 9 community based settings.

Our mission is to work with and for people with intellectual disability so that their rights are upheld in line with international agreements by cooperating with government departments and other stakeholders.

One of the main goals of ÉFOÉSZ is to support people with intellectual disability to have equal rights and equal opportunities and to have a say in decisions which affect them as active members of society.

I. Statistics on people with intellectual disabilities and people under guardianship

ACCORDING TO THE 2001 census there were 577 006 people with disabilities in Hungary, which was 5.7% of the population. The proportion of people with intellectual disabilities was nearly 10% (56 963), from which:

- 7% were employed, which is 3 992 people;
- 1.2% were unemployed, which is 671 people;
- 47.2% were inactive (on pension, disability pension, disability benefit), which is 26 903 people;
- 44.6% were dependent¹, which is 25 397 people.

According to the National Council of Justice of Hungary, this table shows the number of people who were put under guardianship between 2001 and 2005.

Year	Number of people who were put under plenary guardianship	Number of people who were put under partial guardianship	Total number of people who were put under guardianship
2001	1518	956	2474
2002	1667	859	2526
2003	2146	1339	3485
2004	2235	1805	4040
2005 (until 24 Oct.)	1692	1455	3147

From the figures above, we can see that the number of people who were put under plenary guardianship is significantly higher than the number of people who were put under partial guardianship. We can also see that the total number of people who were put under guardianship is constantly increasing.

II. Legal background regarding legal capacity and guardianship

THE MAIN REGULATIONS of legal capacity and guardianship can be found in Act 4 of 1959 on the Civil Code and in Act 3 of 1952 on the Civil procedure, but there is also an important Article in the Constitution² which says that *the right to vote*

shall not be granted to persons who are under guardianship which limits or excludes their capacity.

According to the Civil Code, everyone has full legal capacity unless they are **limited** or **excluded** by the law³. Currently there are two types of limitation⁴ of capacity:

■ One is the **general limitation**, when a court finds that an adult's *capacity is generally limited in all areas of life because his/her discretionary power to conduct his/her own affairs is permanently or periodically reduced to a significant extent as a result of his/her mental state, intellectual disability or addiction.*

■ The other one is the **selected limitation**. In this case the adult has full legal capacity in all areas of life except in selected matters, in which his/her capacity is limited. The Civil Code lists nine groups of matters for example matters concerning inheritance, health/medical care, disposition on personal property or real estate etc.

III. Capacity to work and capacity to enter into job contracts

THE SITUATION IN HUNGARY concerning the employment of people with legal incapacity is not clear. People with legal capacity are under plenary guardianship. Hungarian people with intellectual disabilities can enter into job contracts, unless they have legal incapacity, in which case they are generally considered as people without working capacity.

According to the Labour Code *People with limited legal capacity can enter into contracts of employment⁵*, but the Code does not say anything about people with legal incapacity.

According to the Civil Code *Legally incapable persons' legal declarations are invalid except in a very few cases. In some cases a guardian may be allowed to act on behalf of the person with legal incapacity.⁶*

If a person with limited legal capacity or legal incapacity wishes to escape from a contract he/she has entered into, he/she must show that he/she is legally incapable or has limited legal capacity and that this lack of capacity means that he/she does not have capacity to fulfil the contract in question.⁷

If someone with a lack of legal capacity deceives a person with whom he/she enters into a contract, the person who does not have full legal capacity should take responsibility and can be forced to fulfil the contract in question.⁷

When we talk about problems in the field of the employment we mean the open labour market and "sheltered employment" as well.

¹ Dependents are those who are not included in the category of employed, unemployed or inactive persons, because in most cases they do not have earnings, income and they are looked after by a person or an institution. Dependents are for example children under the age of 15, if they are not students.

² 70.§ (5)

³ 11.§ (1)

⁴ 14.§

⁵ 72.§ (2)

⁶ 15/A.§ (1)

⁷ 16/A.§ (1)-(2)

The facts are concerning employment and legal capacity are:

- 1) People with legal incapacity are not allowed to enter into a job contract either in the open labour market or in sheltered employment.
- 2) It is not possible for a guardian to sign a job contract on behalf of a person with legal incapacity.
- 3) Until recently, if a person with legal incapacity wanted to have a legal job contract, the only possible way was that their guardian signed the job contract on their behalf. Nowadays, employers will not accept the signature of the guardian because the guardian cannot be responsible and accountable for the person with legal incapacity. Employers say that neither the person with legal capacity nor the guardian can be responsible for any incidences or accidents. The Ministry of Social Affairs, the Ministry of Justice, the Ministry of Economy and the Prime Minister's Office all agree with this.
- 4) The source of the problem is that the Hungarian legal system does not distinguish between capacity to work and legal capacity.

IV. Supported decision-making

IN 2006, THE HUNGARIAN PARLIAMENT adopted the 10/2006 (II. 16.) Resolution on the New National Programme on Disability Affairs for 2007-2013. Following the proposal of

ÉFOÉSZ, the principle of supported decision-making was integrated into the Resolution as follows:

*The principle of protecting the personal and special rights of people with disabilities must prevail in all general rules and regulations (e.g. guardianship, caretaking) relating to them. The principle of supported decision-making by people with disabilities, as opposed to decisions made by professionals, means that people with disabilities should be supported in their own decision-making. The person's individual capacity will dictate the level of decision making but wherever possible they should be involved to as great an extent as possible. In order to make use of this principle, the Government must help people with disabilities by providing the necessary resources to create a network for supported decision-making.*⁸

V. Conclusion

OUR ORGANIZATION IS TAKING STEPS to help people with intellectual disabilities have the same rights as others.

Hungarian legislation on legal capacity and guardianship will be changing in the near future, so ÉFOÉSZ is working hard to move towards a better regulation based on the principles of supported decision-making. ★

⁸ Chapter I.

The problems of Guardianship Law in Lithuania

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Some people with intellectual disabilities have difficulties dealing with their personal affairs. The system of guardianship was therefore created to protect them. Unfortunately, many people lose their rights when they are placed under guardianship. This is the case in Lithuania, like in many other countries. People under guardianship cannot make even the most basic decisions. They are also not allowed to sign a labour contract. This means that they cannot be legally employed. Lithuanian law allows for some people to be put under partial guardianship. Unfortunately, this is not the case for people with intellectual disabilities. They are always put under full guardianship.

Certaines personnes handicapées mentales ont des difficultés à gérer leurs propres affaires. Le système de tutelle fut donc créé pour les protéger. Malheureusement, dans beaucoup de pays, les personnes perdent leurs droits lorsqu'elles sont placées sous tutelle. C'est notamment le cas en Lituanie. Les personnes sous tutelle ne peuvent même pas prendre la plus petite décision. Leur signature n'est même pas valable. Elles ne peuvent donc pas signer de contrat de travail et avoir un emploi. La loi en Lituanie offre la possibilité d'être placé sous tutelle « partielle ». Mais malheureusement, ce n'est pas le cas pour la plupart des personnes handicapées mentales. Ces personnes sont le plus souvent placées sous tutelle complète.

Manche Menschen mit geistiger Behinderung haben Schwierigkeiten, ihre persönlichen Angelegenheiten zu klären. Das Konzept von Vormundschaften wurde entwickelt um Menschen zu schützen. Leider verlieren viele Menschen ihre Rechte, wenn sie unter Vormundschaft gestellt werden. So ist es in Litauen, wie auch in vielen

anderen Ländern. Menschen unter Vormundschaft dürfen nicht einmal die einfachsten Entscheidungen selbst fällen. Sie dürfen auch keinen Arbeitsvertrag selbst unterschreiben. Das bedeutet, sie können nicht rechtlich korrekt eine Arbeit bekommen. Das litauische Recht erlaubt es auch, unter Teilvormundschaft gestellt zu werden. Leider gilt dieses Recht nicht für Menschen mit geistiger Behinderung. Sie werden immer unter Vollvormundschaft gestellt.

“HUMAN RIGHTS AND FREEDOMS shall be innate,” states the Constitution of the Republic of Lithuania. It means all people should enjoy the same human rights in equal measure. All persons are entitled to live, work, participate in the community, etc. Also, all people are entitled to make their own decisions, which is a basic human right. However, in some cases an adult, due to his or her mental disability, a disease, profound physical or sensory disability, insufficiency of his/her personal faculties or a similar reason, is incapable of making autonomous decisions concerning any or all of his/her personal or economic affairs, or understanding, expressing or acting upon such decisions, and who consequently cannot protect his or her rights. It also should be taken into account that the number of elderly people is rising steadily in Lithuania as in all other EU countries, due to medical advances and improved living conditions. Mental faculties often decline with age, and therefore all such people may be vulnerable and in need of measures of protection.

The guardianship system exists as a “protective” mechanism meant to safeguard the human rights of vulnerable people. Such a system exists in almost every jurisdiction in the world because it is widely accepted as a good mechanism of protecting individuals who are deemed incapable of managing their personal affairs. In Lithuania, guardianship is being established with the aim of exercising, protecting and defending the rights and interests of a legally incapable person. Thereby, guardianship is a legal relationship established by a court process between a person who is not able to make personal decisions and the person appointed to make decisions on his/her behalf.

However, guardianship is also the greatest human rights issue affecting incapable individuals today in Lithuania. It has a profound effect on the lives of those placed under its protective status. In many cases adults who are placed under full guardianship lose their right to make even the most basic decisions because they lose their legal personality. Very often people under guardianship are forgotten and left in big residential institutions. There are also many conflicts about control of finances, because an adult under plenary guardianship cannot make any legally valid transactions regarding his/her property.

Issues of capacity and guardianship in Lithuania are regulated under the Civil Code and the Civil Procedure Code. According to Lithuanian law, a person acquires full legal capacity at the age of 18 and has the same rights and responsibilities as other adults. However, the Civil Code specifies exceptions to this rule for adults recognized as legally incapable by the courts. Article 3.277 of the Civil Code states that “an adult person declared legally incapable by the court shall be placed under guardianship by a court judgment”. In such cases the person loses all his/her rights

and care is assigned to an appointed guardian acting on his/her behalf. According to the article 3.240 of the Civil Code, a guardian represents his/her ward under law and defends his/her rights and interests without any special authorization.



The guardian also is entitled to enter into all the necessary transactions in the interests and on behalf of the represented legally incapable ward. It is necessary to mention that guardianship of a person subsumes guardianship of the person's property, but if necessary, an administrator may be designated to manage the person's property. Generally, the guardian in Lithuania has both decision-making authority over the adult and an obligation to protect the adult's welfare.

There is no precise data on how many people in Lithuania are recognised as legally incapable by the courts due to intellectual disabilities. Usually, people who have a more severe level of intellectual disabilities are declared as having legal disability status and are placed under plenary guardianship at the age of 18. Such individuals with intellectual disabilities lose all the civil, economic and other rights usually enjoyed by other adults. This includes the right to work, to sign a work contract, participate in work activities or receive a salary. People under guardianship are not allowed to sign labour contracts and consequently they cannot be legally employed. Thus, they are technically legally prohibited from working. The laws in Lithuania do not recognise that people with intellectual disabilities can be capable to an extent to use at least some of their rights or freedoms according to their understandings or abilities, as well as to act at their own discretion.

Actually, Lithuanian law provides for the possibility of placing people under partial guardianship. However, this type of guardianship is used only when the individual is abusing alcohol, drugs, narcotics or toxic materials. Also

article 3.279 of the Civil Code provides for an option in which a physically able person can be assigned guardianship upon request, if the person cannot carry out his or her rights or duties due to their state of health. Nonetheless, only persons with physical or other medical disabilities can make use of this opportunity established by the law. The law requires plenary guardianship in the case of mental disabilities, including intellectual disabilities.

In Lithuania the procedure to place a person under guardianship is initiated when a person is considered unable to comprehend the significance of, or to control, his/her actions, due to mental or intellectual disability. Article 2.10 of the Civil Code states “natural person who as a result of mental illness or imbecility is not able to understand the meaning of his actions or control them may be declared incapable. The incapable person shall be placed under guardianship.” A request for guardianship can be filed by the spouse, parents or children over 18 of the person concerned, as well as the social care institution or the prosecutor. This process is regulated by The Code of Civil Procedure. The Code states that the court must designate psychiatric expertise and examine other relevant medical documents when reviewing the civil case for certifying a person as requiring guardianship.

There are also some requirements for the guardian themselves. Only a competent person can be assigned as a guardian. The person to be appointed as a guardian must also give written consent to his/her appointment. The moral and other values of the guardian, his/her ability to carry out the duties of the guardian, his/her relationship with the ward, the wishes of the ward and other relevant circumstances should be taken into account at the time of the designation of the guardian.

The court decision concerning guardianship can be appealed by the person to be placed under guardianship and by other persons involved in the case within 30 days of

the court's decision. However, the person concerned does not have the right of cassation to overrule the court's final decision concerning his/her guardianship. The Civil Procedure Code also indicates that in cases where the individual's condition is cured or his/her health condition improve, the court can certify an individual as no longer requiring a guardian. Unfortunately, this almost never happens in practice.

There are municipal or regional institutions of guardianship concerned with the supervision and control of the actions of guardians. These institutions supervise the designated guardians on a continual basis in matters relating to the proper performance of their duty to protect the rights and interests of the ward. If guardians are not fulfilling these duties properly, by ensuring the protection of the rights and interests of the ward or by abusing the rights of the ward for their own aims, they can be removed from their duties. If the guardian's actions have inflicted harm on the ward, the ward must be compensated for this. The right to go to court for removal of a guardian is undertaken by the care institutions or the prosecutor. Also the court may relieve the guardian of his/her duties if he or she is unable to perform these duties due to his/her illness or the illness of a close relative, his/her financial situation or other important reasons. Guardianship ends when the court judgement declaring the person legally incapable becomes *res judicata*.

The guardianship model in Lithuania is a traditional type of system, where the typical legal response is deprivation or restriction of legal capacity coupled with the appointment of a guardian who represents the incapable adult in almost all matters. Incapable people are in a weak position due to their incapacity and they can easily be the object of abuse. Today, guardianship in Lithuania is a “legal death”. Therefore the less restrictive alternatives to guardianship (such as supported decision-making) should be used. ★

Europe in Action 2007:

Civil Rights for Everybody!

Ulrich Hellmann

The Head of Legal Department Lebenshilfe Germany

Guardianship legislation differs from one European country to another. However, hopefully all European countries will adopt the UN Convention for the Rights of People with Disabilities. Article 12 of this Convention speaks about the legal status of disabled people. It says that all people are equal before the law. It also says that disabled people should be given support to exercise their rights. Therefore, when each state adopts the Convention, they will have to ensure that their legal system is compatible with article 12. The Convention was discussed at the Inclusion Europe's annual conference “Europe in Action 2007: Citizen's Rights for All!” in Warsaw. The final resolution of the conference will be a useful instrument to improve the legal status of people with disabilities in Europe.



Ulrich Hellmann speaking at the Europe in Action

Les lois sur la mise sous tutelle sont différentes d'un pays européen à l'autre. Cependant, tous les pays européens vont adopter la Convention des Nations Unies sur les droits des personnes handicapées. Or cette Convention, dans son article 12, parle du statut juridique des personnes handicapées. Elle déclare que toutes les personnes sont égales devant la loi. Elle déclare aussi que les personnes handicapées ont droit au soutien nécessaire pour exercer leurs droits. Quand ils adopteront cette Convention, les États devront donc s'assurer que leurs lois sont en accord avec cet article 12. Ces questions ont été discutées à la conférence annuelle d'Inclusion Europe « Europe en action 2007 : Citoyenneté pour tous ! » à Varsovie. La résolution finale de cette conférence sera un instrument fort utile pour améliorer le statut juridique des personnes handicapées en Europe.

Das Recht über Vormundschaft unterscheidet sich in jedem europäischen Land. Dennoch: Alle europäischen Länder werden hoffentlich das Abkommen der Vereinten Nationen über die Rechte der Menschen mit Behinderungen annehmen. Dieses Abkommen spricht in Artikel 12 über den rechtlichen Status von behinderten Menschen. Es sagt, dass alle Menschen vor dem Gesetz gleich sind. Es sagt auch, dass Menschen mit Behinderungen unterstützt

werden sollen, damit sie ihre Rechte wahrnehmen können. Wenn die europäischen Länder das Abkommen der Vereinten Nationen annehmen, muss jedes europäisches Land sicherstellen, dass ihre Gesetze mit diesem Artikel 12 zusammenpassen. Solche Fragen wurden bei der Jahreskonferenz von Inclusion Europe „Europa in Aktion 2007“ in Warschau diskutiert. Die Abschlusserklärung der Konferenz wird ein nützliches Instrument sein, den rechtlichen Status von Menschen mit Behinderungen in Europa zu verbessern.

WHEN ADULTS who have an intellectual disability have difficulties taking care of their legal issues, they may need personal support. This might be necessary, for example, when signing contracts, filing applications for social benefits or consenting to medical treatment. For this purpose, most jurisdictions provide for a court appointed support person, who under current models of guardianship legislation is usually entitled to make legal decisions on behalf of the person with a disability who has been placed under partial or full guardianship.

Guardianship legislation is an issue of continuous discussion and change in all member states of the European Union. Most countries of continental Europe have developed laws and their respective practical concepts of legal support and representation over centuries, with regulations of old Roman Law as a common root. It is only since the last decades of the 20th century that a number of countries have initiated major reforms based on a more flexible approach in order to enable the courts to provide legal support and representation by following the principle of the least restrictive intervention in the legal status and the right to self determination of adults with an intellectual disability. Austria with its new “Sachwalterschaftsgesetz” (law on the appointment of curators for handicapped persons) of 1984 was one of the **proceeding** countries, followed by Germany with the “Betreuungs-gesetz” of 1992, resulting with the complete abolishment of an “incapacitation-procedure” in

both of these countries. More recently, France made an important amendment to its guardianship laws (**procurement** of the right to vote for people under guardianship care), while Italy introduced a new flexible measure of legal support alongside the traditional guardianship.

In contrast, a shift towards modern legislation to codify measures of legal support and representation on behalf of adults with intellectual disabilities within the Anglo-Saxon common law countries can only be monitored for some past years. Thus, Scotland (Adults with Incapacity Act 2000) and England (Mental Capacity Act 2005) have passed completely new laws. In Ireland legislation efforts are currently being made in preparation of a corresponding law. This effort is intensively supported by Inclusion Ireland (NAMHI), the Irish member organization of Inclusion Europe.

In many countries of Central and Eastern Europe the issue of legal support for adults with intellectual disabilities and corresponding guardianship legislation moves but slowly into the focus of interest of policy and legislation. Within the judicial systems, the public administrations, and often even within the disability movements of some countries, an attitude still prevails which does not accept the ability of persons with an intellectual disability to become involved in their personal legal affairs. This is against a human rights based approach to acknowledge the principle of equal citizenship, including the right to self-determination. The

procedure of legal incapacitation is still regarded as the logical consequence that must be taken in order to make decisions for and on behalf of persons with disabilities. whereas until now little interest was turned to the consequences of a complete deprivation of one's legal capacity, which not only turns these adults legally into "non-persons" in terms of participation in personal decision making procedures, but includes the right to marry and to participate in elections.

For the Polish Parents' Association for the Mentally Handicapped (PAPMH) this situation was reason enough to publicly address various inadequacies and shortcomings in both law and practice of the guardianship system in a joint effort with the European umbrella organization "Inclusion Europe" at the international symposium "Europe in Action 2007 - Equal Rights for All!", held in Warsaw from May 10-12, 2007. More than 150 participants from 30 countries took the chance to thoroughly exchange their experiences with guardianship regulations and their implementation in their respective countries. The President of Inclusion Europe, Ingrid Körner pointed out the great importance of the UN Convention on the Rights of Disabled Persons for the symposium, which had been signed on March 30, 2007 in New York by all member states of the European Union. By force of ratification by 20 states, this binding treaty of international law is regarded as a very important and visionary instrument for the protection and advancement of the rights of people with disabilities all over the world. Among the most important regulations of the 50 articles within the Convention are specifications to provide for accessibility (article 9), the right to live independently and be included in the community (article 19), the right to inclusive education (article 24) and the right of persons with disabilities to work on an equal basis with others (article 27).

Article 12 - "Equal Recognition before the Law" - contains regulations acknowledging equal legal capacity as well as the obligation of states to provide the necessary support that persons with intellectual disabilities might need to exercise their rights. This is in itself a major breakthrough in light of the still predominant principle adhered to in most systems of guardianship law, which still provide for a formal procedure of incapacitation, followed by the appointment of a legal representative (guardian) who is entitled to act as a substitute decision-maker on behalf of the incapacitated person.

In contrast to this, Article 12 of the UN Convention clearly postulates the equal legal status of legal capacity of people with disability, which covers the "ability to have rights" as well as "the ability to act", and, furthermore, sets a clear priority of "supported decision-making" over "substituted decision-making". This basic paradigm shift was one of the key-issues of the Warsaw conference "Europe in Action 2007": How could Article 12 of the UN-Convention influence the goals of the symposium to bring about change to the guardianship systems of EU Member States?

Every state that ratifies the UN-Convention will have to carefully examine its laws on incapacitation and guardianship to ensure that they are compatible with Article 12. As an example, the German Betreuungsgesetz (a law

providing legal assistance and representation for people with intellectual disabilities), does not require a statutory and formal judgment of legal incapacity anymore. Instead, it supplies the disabled individual with a legal assistant to provide support with legal issues demanding settlement and, thereby, does not restrict the individual's ability to act on their own behalf. Nevertheless, the legal "Betreuer" is authorized to act as a proxy in legal matters on behalf of the person if the "Betreuer" is convinced that it is necessary to do so. First of all, however, the "Betreuer's main task is to facilitate the self determination of the supported individual and to obey his or her wishes, as long as this is appropriate for the well-being of the supported individual. Therefore, the German legislation on legal assistance is certainly one of the most progressive concepts on the international level. In view of the aim of the convention, however, it must be critically examined whether to call for a substantial development of improved structures providing assistance of supported decision-making for people with intellectual disabilities. This would enable an, "assisted self determination" that allows for settlement of individual legal matters, which in turn would help to limit the relatively high figures of Court orders for "Betreuung" in accordance with the German Civil Code.

At the Warsaw conference, it was reported that in Poland it is still quite customary to incapacitate individuals with intellectual disabilities, which degrades their legal status to the infant's level. In these cases, a guardian is authorized to decide on all matters as a legal proxy on behalf of and for the incapacitated. Often courts agree on incapacitation procedures even without any personal hearing of the respective individual. For the individuals effected this is often the beginning of a predetermined life without civil rights, which may result in accommodation in large institutions, the deprivation of education and employment, and to a large extent without any chances to develop a private sphere, establish partnerships or participate in political elections. Reports from Hungary and Lithuania described that incapacitated persons in these countries are denied access to employment and occupation, because their own as well as a guardian's signature are not acknowledged to validate a work-contract.

A remarkable number of more than 50 self-advocates from Poland participated in the Warsaw conference and underlined their demand to be accepted and respected as citizens with equal rights who are enabled to lead self-determined lives. In jointly conducted working groups and in collaboration with self-advocates from other countries and experts they shared their experiences and hopes for the best possible organization of their daily lives. The discussions centered on autonomous accommodation independent from the parental residence, participation in working life, the right to marry and to participate in elections.

Michael Bach, executive director of the "Canadian Association for Community Living" (CACL), the Canadian member organization of the worldwide umbrella organization "Inclusion International", gave a remarkable presentation that focused on reflections about a concept for a "Supported Decision-Making" system as put forward in Article 12 of the

UN Convention. The basic assumption of the Canadian concept is that each individual - regardless of the severity of a disability - has the ability to act and is usually embedded in a network of persons who know him or her and whom he or she may trust. With the help of this network it is regarded as possible to determine the personal wishes of the individual and to communicate them in a legally valid way as his or her own decisions. Thus, the traditional model of "substituted-decision making" is obsolete. A proper

implementation of this roughly outlined concept of CACL requires a well established framework of legal regulations and measures which will have to assure more than just assistance, but also safeguards for the protection of persons with intellectual disabilities against exploitation and abuse alongside a control mechanism monitoring quality and assistance. CACL is planning to implement the concept in model projects in Canada, where guardianship legislation lies within the responsibility of the provinces.

The "Final Resolution" of the Warsaw conference may serve member associations of Inclusion Europe as a useful tool for political lobbying in the fight for improvement of the legal status of people with intellectual disabilities throughout Europe:

Resolution of the Conference "Europe in Action 2007" on Citizens' Rights for All on 12 May 2007 in Warsaw, Poland

The UN Convention on the Rights of Persons with Disabilities is an important step forward to accept persons with intellectual disabilities as full citizens of their countries.

■ Inclusion Europe calls upon all European governments to ratify the UN Convention by the end of 2007 and to transfer its contents into their national laws.

Article 12 is of utmost importance for persons with intellectual disabilities. It states that all persons, irrespective of kind and degree of their disability, are equal before the law and have the same rights as all other citizens. All people with disabilities are seen by Article 12 as persons with "legal capacity on an equal basis with others in all aspects of life."

The participants of the "Europe in Action 2007" conference therefore are clear that:

- The term "legal capacity" means not only to have rights and duties, but includes the right to exercise legal capacity.**
- National guardianship or legal assistance laws that deny people their full legal capacity and instead provide for substitute decision-making by a third party are not in agreement with Article 12.**

Many persons with intellectual disabilities and their families and friends have, for many years, fought for self-determination, individual autonomy and independence. Sometimes it is difficult to take a decision as some situations in daily life are complicated. The answer of Article 12 of the Convention is that in such situations the States Parties of the Convention are obliged to "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."

The participants of the "Europe in Action 2007" conference therefore demand that:

- All States establish a legal foundation for a supported decision making model that helps people with disabilities to exercise their rights, distinct and separate from substitute decision-making models.**
- All States should instantly take all necessary steps to establish legal models and networks to give people with intellectual disabilities full access to supported decision-making.**
- They should do this in close consultation and with active involvement of persons with intellectual disabilities, their families and their representative organisations.**

Inclusion Europe is a non-profit organisation that campaigns for the rights and interests of people with intellectual disabilities and their families throughout Europe. Respect, Solidarity and Inclusion are the fundamental values shared by all members of our movement of and for people with intellectual disabilities and their families.

Inclusion Europe is represented in 36 countries by national and regional organisations of parents and self-advocates. We are represented in:

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Photos: Inclusion Europe Archive

Design: Jan Matoska

Supported by the European Commission

Call for contributions

If you would like to inform the network about your events, projects or campaigns connected to intellectual disability issues, please send us a short description of such activities and we will include it in the next issue of our newsletter or post it on the website. Please send all contributions to information@inclusion-europe.org

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