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# Justice, Rights and Inclusion for People with Intellectual Disability

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# Justice, Rights and Inclusion for People with Intellectual Disability

## **Abstract**

[Excerpt] Adequate laws in the area of legal incapacitation and guardianship are of fundamental importance, especially for adults with intellectual disability. For them it means recognizing their individual rights to self determination. It also signifies a move away from treating the person who lacks capacity within an old-fashioned model of care, based solely on a medical diagnosis. When present laws on capacity and/or the way they are implemented are examined against the backdrop of the human rights based model of "inclusion within the society" we begin to see their inadequacies.

## **Keywords**

work, disabilities, person, national, state, government, economic independence, freedom of choice, programs, processes, benefit, policies, equality, law, model

## **Disciplines**

Disability Law | Human Rights Law

## **Comments**

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# Justice, Rights and Inclusion for People with Intellectual Disability



**Inclusion Europe**

Report

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## 1. Introduction

Supported by the European Commission, Inclusion Europe and its members and project partners from five European countries have conducted a survey to identify the situation regarding three issues which are very important for people with intellectual disability and their families:

- Legal capacity and guardianship
- The right to services and support
- Access to rights and justice

The membership of Inclusion Europe in almost all EU and accession countries responded to a questionnaire about these issues. For this publication, the project partners have selected the reports from Sweden, Germany, Spain, France, Ireland, Belgium, the Netherlands Slovenia and Poland to provide an overview and impression about the very heterogeneous situation found in European countries.

Adequate laws in the area of legal incapacitation and guardianship are of fundamental importance, especially for adults with intellectual disability. For them it means recognizing their individual rights to self determination. It also signifies a move away from treating the person who lacks capacity within an old-fashioned model of care, based solely on a medical diagnosis. When present laws on capacity and/or the way they are implemented are examined against the backdrop of the human rights based model of "inclusion within the society" we begin to see their inadequacies.

The situation of service provision for people with intellectual disability in the European Union and the accession countries is in all countries far from adequate. It is unacceptable that the quality and the extend of service provision depends on where a person lives in the Union, or even within a member state.

The access of people with intellectual disability to rights and justice is by no means guaranteed. Legal structures and proceedings are generally not accessible for them and their legal representation is not very well organised.

From the responses it became clear, that these three issues are closely linked and that there is no consistency in the legislation in the EU member states and the accession countries. Inclusion Europe's members reported unanimously that the present legislation on legal incapacitation, as well as the lack of access to rights and justice lead in all countries to a very great danger of social exclusion for people with intellectual disability. Unlike other excluded groups in society, they are even denied – either by legal incapacitation or by the design of the legal system – the possibility to fight against their exclusion from society.

Based on these findings, Inclusion Europe has formed a consortium with a number of different actors which will develop approaches and strategies that allow people with intellectual disability, their families and their associations at national and European level to fight for better legislation regarding legal incapacitation and guardianship and to gain better access to their rights. This will be an important contribution towards their increased inclusion in European society.

Françoise Jan  
President  
Inclusion Europe

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## 2. Legal Capacity and Guardianship

All persons with intellectual disability have the same rights as the rest of society. As such they are entitled to live, work and participate in the community in the same manner as everybody else. They are entitled to make decisions, which is a basic human right.

However, there are many who have difficulties in the practice of everyday decision-making. Difficulties may arise in relation to giving consent to medical treatment, care and personal welfare issues and other complex issues such as relationships and sexuality.

Fundamental questions arise as to whether a person with intellectual disability is able to comprehend and retain information relating to a particular decision. When persons are unable to understand the consequences of a decision they are deemed not to be competent and therefore deemed incapable of giving valid legal consent to a particular decision. When this happens questions arise as to who is then entitled by law to take decisions on behalf of individuals that lack legal capacity.

The freedom of decision-making, legal incapacitation and guardianship must be seen individually for each person with intellectual disability. While some people are able to live quite independently and need only very little support, others might need the protection of partial legal incapacitation and guardianship. Legislation regarding full or partial legal incapacitation and guardianship must reflect these individually different needs.

However, legal incapacitation remains a very strong infringement of the personal rights of a person and can lead to a situation where persons have no possibilities to defend their rights. This can make them very vulnerable to social exclusion. Therefore, it is very important that adequate and accessible revision procedures are in place that give the person with intellectual disability the chance to revise decisions about their legal incapacitation.

The following country reports from some strategically selected countries in Europe provide an overview about existing legislation and practice. They make clear that there is no common approach to the issue in the European Union and the accession countries.

### 2.1 Country Reports

#### **Spain: Guardianship for protection and participation**

The Spanish system establishes three types of protection for the person and property of the persons who have been declared legally incompetent: **guardianship**, **protection (*curatela*)**, or partial incapacity) and the **judicial advocate**. The main difference between guardianship and protection (*curatela*) is that the former provides more extensive protection than the latter, depending on the degree of discernment of the incompetent person. The judicial advocate is established in cases of conflict of interests between the legally incompetent person and his or her legal representatives or the guardian, and for periods in which for any legal cause these latter persons are unable to exercise their functions, while awaiting appointment or during a process of dismissal.

Incapacitation and the type of protection are subject to a court decision. The appointment of the guardian is done by a judge who establishes guardianship after hearing the closest family members and any other persons the judge considers suitable. The judge also hears the concerned persons if they have sufficient "use of reason" and always if they are above the age of twelve. Guardianship is exercised under the supervision of the Public Prosecutor who acts *ex officio* or at the request of any interested party. The Judge, *ex officio*, at the request of the Public Prosecution, of the ward or of any interested person, may determine that the guardian be dismissed and may appoint a judicial advocate to take care of the incapable person's interests until such time as

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a new guardian is appointed. If the guardian fails to meet his obligations or shows clear incompetence in meeting them or when there are serious constant problems, the ward or any other interested person may request that the guardian be dismissed.

The institution of guardianship exists to defend and protect the person's rights and interests. It is exercised exclusively for the benefit of the ward and is an obligation. The guardian must make every effort for the ward to be able to lead a normal life. Acting as guardian does not imply the annulment of rights but rather the complementing of rights. The person receives protection in order to act. Guardians take on the commitment to promote their wards personally and socially, encouraging them to recover their capacity and supporting them in all aspects of their lives. When guardians are legal entities, these should have a team of specialists to carry out the tasks of guardianship and to professionally achieve the greatest possible convenience for the ward.

In cases in which the legally incompetent person wishes to carry out a highly personal act, the judge must authorise this act if sufficient expert information is obtained to accredit the person's capacity for this specific act. Otherwise, the act will have no legal effect. In dealings with justice, the administration, the police, etc. the incompetent person must always be represented by his or her legal representative who should guarantee his rights and guarantees. The guardian must represent the ward in all cases, ensuring that the person is able to exercise his or her rights.

Legal incapacitation should be seen in the positive sense that it allows people with a lack of capacity to act through their legal representatives or with assistance from others who complete their capacity. To this extent, incapacitation actually creates capacity rather than determining incapacity or taking away capacity. The aim is to give such citizens all the protection they need, but only what they need, respecting their freedom as far as possible and their capacity to decide on essential aspects of their lives. Incapacitation and being subject to the guardianship system are not incompatible with support and training for taking decisions. More specifically, professional social workers in guardianship entities work together with the community services dealing with such persons, establishing objectives for personal promotion.

There are a few courts in Spain that specialize in incapacity and guardianship. Where there is no specialist court, problems may arise because judge has to deal with all sorts of legal matters and has no specialised team. Courts obviously require assistance and guidance from multi-disciplinary teams (social workers, psychologists, neurologists, etc).

Incapacitation is an exceptional measure that is often unnecessary. It does not resolve the ward's personal or social problems. What it does is to afford protection at all times, and capacity for the person to defend his or her own interests. A ward's personal and social problems may be the same as those of a capable person. Solutions must be found through the provision of services, access to jobs, leisure activities, normal housing, etc.

### **Sweden: System of guardianship with a strong role for municipalities**

At the age of 18 every citizen is regarded as fully responsible for the consequences of whatever decisions and/or actions that he/she decides upon. The only form of limitation regarding legal capacity existing in Sweden is called **trusteeship**. A person for whom a trusteeship is appointed loses his/her legal capacity in specific matters. An alternative guardianship is called **custodianship or "good man"**. Even though the adult person receives all necessary support, he/she keeps full legal capacity.

Every municipality in Sweden must appoint either a single public trustee or a committee of public trustees with the task of supervising the administrative work carried out by guardians, custodians and trustees. This supervision aims to guarantee that people such as elderly, sick and disabled, as well as minors who are unable to exercise their own rights, administer their property or pro-



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vide for their own needs, suffer no loss of legal rights. If a need of support is verified by the municipality, it must be provided for no matter if the legal incapacitation is continuous, single-case oriented or for specific areas.

The rules of custodian- and trusteeship are settled in the Code of Parenthood and Guardianship (FB 11:4). The code states that "if, because of sickness, arrested mental development, a weakened state of health or the like, a person needs assistance in safeguarding his/her rights, administering his/her property or providing for his/her needs, the Court shall, if needed, appoint a custodian or "good man" for him/her." The initiative might come from the adult him/herself, but more likely from someone who has a thorough knowledge of the person and his/her living conditions.

A professional e.g. of a social welfare agency is not allowed to apply for custodianship. They are only obliged to report the need for a "good man" to the supervisor of the public trustee. When the public trustee receives an application regarding custodianship and/or trusteeship, an investigation starts to find out if there is a need of support regarding individual inabilities. If the trustee finds that a persons needs can be provided for in a less restricted way than by legal incapacitation, this course of action will be taken.

An application has to be accompanied by a social welfare report giving the reasons why an application for a "good man" is being made. If possible, this should be approved by the adult. If not, the application must be accompanied by a doctor's certificate, stating that the person is unable to give his/her approval.

If a person is proposed as a "good man", either on initiative by the adult or by close members of the family, the person proposed shall confirm that he/she is willing to accept the responsibility. If there is no such proposal, the public trustee must find and suggest a custodian considered appropriate by the trustee. After completing the investigation, the public trustee submits the application to the District Court. The adult's relatives are contacted before the Court takes its decision. When the District Court has decided upon a "good man", a custodian authorization is issued.

Custodians and trustees must submit an annual account of their administrative work of the previous year by 1st March. The accounting records are to cover the entire previous year. The public trustee must examine the annual or final accounts and set a fee for the work. Custodians and trustees receive fees for their support work for the adult. The amount of the fees is determined by the public trustee. They also receive compensation for their costs. The fees and compensation are paid from the adult's funds if the income totals more than twice the base amount or if the assets exceed three times the base amount. This obligation is criticized by the national association FUB: The aim of Swedish disability policy is full participation and equality. It is not possible to be "equal" if you have to pay extra because of your impairment. In case of insufficient income or assets, the municipal authority will pay the set fees.

A custodian should act as a "counsellor" and always inform and discuss (if possible) the transactions with the adult. Agreements must be the basis of any transaction. The custodian acts as a legal representative when the person is unable to represent his/her own interest. However, the person with intellectual disability retains his/her legal competence/capacity. A custodian is usually appointed for a person who is unable to manage his/her own financial affairs.

An alternative to guardianship is to give power of attorney to somebody. This is only accepted if the person that gives authority fully understands the actual meaning of the procedure. The authorization has to be witnessed.

The control of guardians is handled by the public trustee. In case of complaints regarding a custodian/ trusteeship, the public trustee immediately has to start an investigation. The adult him/herself can in case of a conflict with the custodian appeal to the public trustee for help.

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A person for whom a trustee is appointed loses the right to decide on the matter covered in the authorization of trusteeship, but in all other respects retains his/her legal competence. Detention of a person can only be carried out after a court decision, which applies to every citizen. Sterilization is not allowed in Sweden anymore. Every citizen above the age of 18 has the right to marry and vote, regardless of any other limitations in legal capacity. Every citizen can be called upon to testify in court. A person under custodianship can still perform everyday legal activities, but the same does not apply to a person under trusteeship.

In general terms, the national association FUB has a positive opinion regarding guardianship in Sweden. A vast majority of custodians and trustees are performing an excellent support and look upon the task very seriously. Nevertheless most guardians are not given the amount of support and supervision they need.

Persons with intellectual disability depend to a large extent on guardian support to be assured full participation and equality. More efforts must be made in every municipality to improve the competence of the guardians e.g. regarding knowledge of legislation and functional impairments.

### **Poland: Traditional guardianship laws with shortcomings in practice**

All persons over 18 years have full legal capacity in Poland. Adult persons with an intellectual disability can become fully or partially legal incapacitated. The procedure of legal incapacitation – because of its social importance – is handled in the district courts by three professional judges. The proceedings can be initiated by family members or the public prosecutor. The rule is to examine the person by a psychiatrist. The court can nominate a curator for the procedure (mainly relatives) if the person must otherwise be regarded as helpless.

Fully incapacitated persons are deprived of their ability to legal action and are subjected to **guardianship** covering all possible legal activities of the person. For some specific actions a guardian must have permission of the family court. The guardian has the obligation to hear the persons concerned and to follow their decisions as far as possible. This is controlled by the court.

Partially incapacitated persons are limited in their legal ability and a **curator** is appointed for specific legal tasks. Both support forms are appointed by the family court (a special division of the local court) just after the information about a incapacitation is received from the regional court.

Persons with full legal incapacitation are unable to marry, make a will, accept their children or become employed. Small daily activities like shopping etc. are possible unless they are very harmful for that person.

Most guardians fulfill their duties on a voluntary basis. If the management of property is very complicated and connected with expenses, a guardian can ask the court for a salary or reimbursement of costs. Courts receive an annual report from guardians and have the right to constantly supervise the guardianship. Curatorship ends when incapacitation is revoked or partial legal incapacitation is changed to full legal incapacitation.

The Polish legal system does not permit sterilization. The final decision on medical treatment and therapy for a person with legal incapacitation is taken by the family court.

The institution of legal incapacitation was created as a legal protection for persons with intellectual disability, which should be used only for their benefit. Despite of this, the old methods, full of stereotypes and the nonflexible way of treatment of persons with disabilities in the Polish courts result in an abuse of this legal institution. Persons with disabilities achieve higher education and social competence. Despite that, possibilities of legal protection which include support do not ex-

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ist in the Polish law system. Even more flexible possibilities mentioned above (partial legal incapacitation) are not sufficiently applied. Proper practice of law enforcement or adequate changes in the law should be promoted in the field of legal protection of the rights of people with intellectual disability in Poland.

The national association PAPMH is acting mainly in the fields of raising awareness about legal incapacitation and its procedure among the parents as well as in its living facilities, in giving notice to courts about the quality of guardianship, and in collecting examples of bad practice for presentation to the Polish Ombudsman, and last but not least in preparing materials for amendments of the existing legislation.

### **Germany: Successful reform under pressure because of high public costs**

At the age of 18, every adult principally reaches full legal capacity, parents' responsibility ends. § 104 BGB (German Civil Code) determines that an adult *who suffers from continuous pathological disturbance of his mental activity*, is legally incapable. However, there is only a single-case oriented use of this regulation about legal incapacity: Any partner of a contract, who wants to cancel the agreement due to legal incapacity, has the burden of proof for the legal incapacity of the contract-partner. The Civil Court usually orders an experts certificate by a psychiatrist. The decision is only valid for the single case.

In the German system of Civil Law, there is no procedure for the determination of continuous legal incapacity for a disabled person anymore.

The "Betreuungsgesetz" (BtG) of 1992 has led to a substantial improvement of the legal situation of people with intellectual disability in Germany. "**Betreuung**" is a new form of guardianship without the precondition of an "incapacitation" of the adult, flexibly tailored to the needs of the person for legal support and representation. The judge determines the sphere of authorization of the Betreuer in each single case (§ 1896 BGB).

For the choice of the Betreuer, the judge has to follow the wishes of the disabled person itself, otherwise there is a ranking of family members, voluntary citizens, professional guardians, public guardians of the local "Betreuung-Authority" (§ 1897 BGB). The Judge selects and appoints the Betreuer. The court controls – with support of the local authority - the Betreuer (§ 1837 BGB), who has to deliver a yearly report. The disabled person can complain with the court at any time about any decision of Court and/or the Betreuer in a legally relevant matter.

The legal position of a person under "Betreuung" is principally not limited. The person can continue to act on his/her own behalf – even within the range of authorization of the Betreuer – as far as the person actually can do so.

The Betreuer has to find out and to obey the wishes of the disabled person, as long as they are not likely to be harmful for the disabled adult. Before taking important decisions on behalf of the person, the Betreuer shall try to find out/discuss the personal wishes of the disabled adult (§ 1901 BGB).

The right to marry is not withdrawn, neither is the right to make a will. The right to vote is withdrawn only in the exceptional (about 1 % of all measures of Betreuung) cases of "Betreuung for all affairs of the adult". The placement of a disabled person in a closed institution against or without personal consent is only allowed with permission of a Betreuer and additional permission of the court (§ 1906 BGB). Continuous or repeatedly applied limitations of the personal freedom of adults living in "open" group homes or similar institutions must also be allowed by the Court (§ 1906 Sec. 4 BGB).

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The sterilization of an adult who is unable to consent is allowed only under the strict conditions of § 1905 BGB, which has led to a substantial decrease of sterilization figures, coming close to a prohibition of the sterilization not based on personal consent.

The private “power of attorney” is an alternative and strongly promoted in Germany in order to avoid (costly) court procedures for Betreuung. However, the power of attorney can only be recommended if a person really has somebody who can be fully trusted, especially for a use of the power of attorney in future situations when the adult lacks capacity to control its use. According to the experiences of LEBENSHILFE the power of attorney in practice is no valid alternative for most people with intellectual disability.

Another alternative would be the intense training and support of people with intellectual disability for self-determination and personal decisions; currently, there is no such structure for supported decision-making in the social/legal-support-system in Germany, which could work as an alternative to court decisions for Betreuung. This could be an additional task for the (non-profit) “Betreuungsvereine”, social associations which – under the current law – have the task to find, train and counsel voluntary citizens willing to become “Betreuer”; however, they are successful only where sufficiently funded for effective work for and with volunteers. Unfortunately, public support for “Betreuungsvereine” is decreasing.

Betreuung in practice works good, besides occasional cases of misuse or misconduct. Figures have passed 1 million cases of Betreuung, causing discussions in the political field to change the law. LEBENSHILFE will have to fight cutbacks of the legal position of people with an intellectual disability.

### **France: System of three measures for legal protection**

Any individual having reached adult age, i.e. 18 years since the Law of 5 July 1974, has the capacity to validly do all acts of civil life. Thus, also any person with intellectual disability is recognized as legally capable of all her/his acts as from 18 years of age. The fact of her/him of being perhaps holder of a disability card involves no restriction regarding this principle. However, Article 488 of the Civil Code made provision for exceptions, the justification being the protection of the interested parties themselves. These exceptions are called “legal safeguard”, “trusteeship” and “protection”.

Any protective measure ceases when the causes which determined it disappear. Otherwise, a protective measure is legally incapacitating a person to different degrees. Protection relies on the mechanism of total incapacity, the trusteeship on incapacity according to the achieved acts.

Any protective measure is pronounced by the “judge of protections” at the person's request to be protected, of his/her partner (unless they do not live together anymore), of his/her parents or children, of his/her brothers and sisters, of the curator or of the tutor (when this involves passing to another more suitable measure), or of the public ministry.

Other parents of the person to be protected, allies, friends, can only give their opinion on the cause to the judge. The same is true for the family doctor and the director of a care facility. When a care facility files for legal protection, the judge of the protections listens to the person to be protected and let him/her know the relevant procedure.

The Civil Code limits the legal capacity of adults considered as not having the intellectual or physical faculties to enable them to engage with understanding in the acts of civil life concerning both their inheritance and their person, as well as those whose behavior jeopardizes their own condition of survival or their family. But these exceptions have to be interpreted in a restrictive

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way because even if they were made in the hope of protection, they constitute an essential infringement of personal freedom. This is why legal protective measures are always decisions of court pronounced by a magistrate: the judge of protections.

All legal procedures are free of charge since 1 January 1978. On the other hand, concerning the fees of the specialist doctor who has to give an professional judgment on each case, it is suitable to inform oneself about the doctor's fees. Indeed, these fees can reach high levels (150€) because this involves expertise (not refunded by Social Security) and not a simple consultation.

The Law of 3 January 1968 created three arrangements for the protection of adults:

- **The legal safeguard** is a provisional measure which can be taken in urgency. The legal safeguard leaves the protected person free to act, but the any act that would be contrary to his/her interests could be denounced more easily by the court.
- **Trusteeship** is addressed to persons who, without being in a position to act by themselves, need to be controlled or advised in the acts of civil life. The judge designates only one person, the trustee, instructed to assist the protected person in the important acts.
- **The protection** is addressed to persons who cannot act by themselves and must be represented in a continuous way in the acts of civil life.

The protective measure has, in theory, to be entrusted to a member of the close family or to an association. More precisely, when the protection or trusteeship is declared vacant, the judge submits the person to the State, which generally entrusts him/her to an association.

It happens very often that vis-à-vis an act, and in particular for measures of trusteeship where the protected adult preserves part of his/her legal capacity, the tutor and the major do not agree. In this case, the judge of the protections decides.

The right to self-advocacy is found in what is called "the person's protection" which is opposed to the "protection of the inheritance". Indeed, for everything that touches the person directly, the person's agreement must be sought since he/she is capable to express and understand.

The right to vote of persons under protection: with the legal safeguard, the person can vote and is eligible; under trusteeship, the person preserves his/her right to vote but is ineligible, and under protection, the person can neither vote nor be elected.

Sterilization of people with intellectual disability is prohibited by the new Law of 4 July 2001 on an adult person whose deterioration of mental faculties constitutes a disability and justified his/her placement under protection and trusteeship. Only when there is an absolute medical counter-indication to contraception methods or the proved impossibility of implementing them effectively sterilization can be practiced. The procedure is subject to a decision of the judge of protections requested by the person concerned, the father and mother or the legal representative of the concerned person. The judge decides after having heard the person concerned. If he/she is able to express his/her will, his/her agreement has systematically to be sought and taken into account after adapted information to his/her degree of understanding was given to him/her. His/her refusal cannot be ignored.

With the legal safeguard, a person can marry in accordance with the common right; under trusteeship, the agreement of the trustee of the judge of trusteeship is necessary; under protection, the marriage is possible only with the agreement of an especially established (if it did not exist) board family to discuss. A meeting does not take place of a board family if both father and mother give their agreement to the marriage.

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The Law of 3 January 1968 created three arrangements of adult protection. On the other hand, it does not come to a conclusion about the advisability of the adoption of a legal protective measure. In the case of a person with intellectual disability, the Law does not make any protective measure obligatory. Very often, however, an adult with intellectual disability suffers from partial or total incapacity to manage his/her own affairs. This is why very often the alternative to a protective measure is a protective measure of fact, i.e. parents behave as tutors while no court decision is given in this direction. The alternative can also be taking over by social aid.

There are training centers for tutors. However, up to now no obligation imposes a specific training to exercise the job of a guardian. The forthcoming reform should require obtaining a diploma to exercise this function.

### **Belgium: Important role of the concept of extended minority**

In Belgium, there are several legal protection measures of which two are most often used. This involves the extended minority and the provisional administration. They are not obligatory. They are determined by the degree of the person's incapacity. These measures protect the person from his/her acts and especially from others. In order to benefit from a protective measure, a request has to be submitted to the competent court and the decision to put the person under a legal status is taken by the judge.

The extended minority applies to persons with severe or profound intellectual disability having begun during early childhood, i.e. before the age of three. The person under extended minority is considered as a minor of less than 15 years. He/She therefore cannot manage his/her person, his/her resources, marry, become parent, vote, etc. The person remains under the authority of the parents or tutor. This measure is definitive, but the legislator wanted to believe in a possible development of the person and set up an alternative measure.

The provisional administration of goods is a procedure where only the person's goods are taken into account and not her/his well-being. This measure applies to persons with mild to moderate intellectual disability but also to persons with mental illness and to elderly people. The person preserves all her/his rights, except for the right to manage her/his goods, which are dealt with by an administrator, designated by the Judge of Peace.

#### **The extended minority**

Parents, the tutor or the prosecutor of the King can initiate the process of legal incapacitation. The judge has a meeting with the person before taking the decision. The person has to be assisted by a lawyer. The judge of first authority bases the decision on a medical certificate as well as on the meeting with the person. There is no re-evaluation of the status but an annual control of the tutor when parents are dead. There is no control at the level of the parents.

Persons who make the request in the court assume the costs of the procedure. When both parents are dead, there is a deputy tutor as well as the tutor. In these cases the tutor has the parental authority on the person. The deputy tutor and the Judge of Peace monitor the tutor. For important decisions, the tutor has to have the agreement of the Judge of Peace.

As long as parents are alive, they have the parental authority and there is no tutor set up. The tutor will be a member of the family; the deputy tutor would be a person of confidence. Under no circumstances they would come from the service where the person lives. The judge designates the tutor and the deputy tutor.

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Normally the tutor is not remunerated for the extended minority. If there is a division of protection, the tutor to the goods is entitled to 3% of the disabled person's income. The tutor has to submit annually an accounting report and a report on the person's well-being. It is returned to the Judge of Peace as well as to the deputy tutor.

The deputy tutor controls the tutor and can call the Judge of Peace if there is any problem. In case of conflict, the disabled person can call the deputy tutor or the Judge of Peace who will evaluate the conflict and decide, either by regulating the conflict or by designating another tutor.

From a legal point of view, it is the tutor who takes the decisions in the person's place. It should be hoped that the tutor takes account of the persons' opinion. As the person is considered as minor, he/she cannot vote, nor marry. The person cannot speak in court for his/her goods, but can be heard for his/her person. If he/she has the capacities, he/she can take the bus and move. The person will be able to buy small things, such as for example bread, but will not be able to buy more important things. The person does not have access to his/her bank account. The tutor will decide about the persons place of accommodation. The tutor has even the right to decide about a sterilization. However, the person remains responsible from a penal point of view.

### The provisional administration of goods

The person, the close family, any person having an interest (support person, etc.), or the King's Prosecutor can initiate the process of legal incapacitation. A meeting is carried out with the Judge of Peace, in the presence of the applicants. The Judge of Peace decides on the incapacity based on the medical certificate as well as on his/her talk with the person.

Currently there are no re-evaluations foreseen, but the administrator has to give annually an accounting report to the Judge of Peace for controlling the financial management. For complaints, there is a possibility to refer to the Judge of Peace. The costs of the procedure have to be paid by the applicant.

The administrator has only the power to take decisions at the level of the person's goods. In the event of important decisions, he/she has to ask for the authorization of the Judge of Peace.

One can become administrator of a disabled person in the sequence of preference predetermined in the law: Spouse, a close family member, a professional or a confidence person (lawyer or notary). The Justice of Peace selects the administrator taking into account the proposals of the applicants and taking into account the abilities of the future administrator. The professional administrator is entitled to 3% of the disabled person's income. The administrator has to give an annual accounting report to the Judge of Peace. The Judge of Peace has the power to limit the role of the administrator or to dismiss him/her of all functions.

The person has all the rights concerning his/her well-being, but it is the administrator who decides at the level of the goods. The managed person is considered as an adult and therefore will be able to marry, have children, have his/her personal effects, to decide where he/she wants to live. For more important purchases the person needs the consent of the administrator, but can manage a small budget alone. This is decided with the Judge of Peace on a case-by-case basis.

### **The Netherlands: Variety of legal measures with need for improvement in practice**

There are three different measures of legal representation in Dutch civil law:

- Full guardianship continuously covers all material and immaterial matters of the disabled person, the guardian has full authority of substitute decision-making.

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- A partial guardianship (“Beschermingsbewind”) covers only material matters (finances, property)
  - A second form of partial guardianship (“Mentorship”) covers only immaterial matters (support, medical care and treatment).

Relatives, family members and the Public Prosecutor are entitled to apply for a measure of incapacitation and legal representation. The judge has to choose the least restrictive measure, the disabled person has the right to be heard and to get legal assistance; a medical expert is always involved in the procedure. In practice often the combination of the two forms of partial guardianship is used as a less restrictive alternative to full guardianship.

In case of full guardianship or guardianship for property, specific periodic financial reports have to be presented to the court, however, practice often is very inadequate: Some guardians have not been asked for a report in 20 years. In case of the partial guardianship for personal support, the judge is free to ask for a report.

Guardians are selected and appointed by the judge, only in case of the partial guardianship for finances and property it does not have to be a natural person, for this measure often a corporation is appointed. Guardians have to respect the abilities of the disabled person, but sometimes guardians are acting rather for their own interests instead of those of the person with intellectual disability. Many judges are not very active in controlling, and difficulties also occur in practice when the judge has to decide about a complaint of a disabled person against the guardian.

The sterilization of a disabled person who is not able to give personal consent is allowed with substitute decision of the guardian, but not when the person with intellectual disability resists. People under guardianship can marry only with permission of the guardian and the court. There is no right to vote or to make a will in case of full guardianship. According to the law, every day legal activities are not binding, however this is generally not a problem in practice.

Alternatives to guardianship such as practical assistance and training do exist, but may carry the risk of insufficient protection, especially when assistance and training is offered by the care-provider.

Control and training of legal guardians must be intensified, so that legal guardians only make substitute decisions when necessary.

The national association FvO in the Netherlands has promoted partial guardianship in specific law, better assistance and control of guardians, as well as improved directives for judges. There is a need to address the general lack of guardians.

### **Ireland: Intensive lobbying for modern guardianship legislation**

The law in Ireland as it relates to capacity and consent for people with an intellectual disability is inadequate and in need of reform. The legal position at present is that there is no form of Adult Guardianship, Adult Care Order or Enduring Powers of Attorney for people with an intellectual disability. The law relating to capacity and consent for the intellectually disabled has not developed systematically and is very different from the law in other Countries.

Although enduring powers of attorney have been legislated for in the past two years but the legislation does not cover people who have developmental delay and who are deemed not capable of giving consent on issues which affect their lives.



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The only legal option available to adults with intellectual disability is to become a "Ward of Court". In practice this usually occurs where there are financial and property issues involved or in some instances where there is evidence of the person involved being at risk of abuse, exploitation or neglect. The process though important in its own right has been criticized as being cumbersome and expensive particularly where there are care and welfare issues involved.

It is proposed by NAMHI that capacity legislation should be based on a justice system that takes account of the values of dignity, autonomy, equality and solidarity of individuals. These should be common to several pieces of associated legislation and policy. It is further proposed that the vision be based on the full text of the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

### **Slovenia: Improvement of individual rights is on the agenda**

People with intellectual disability in Slovenia are under special protection of the Slovenian Constitution. There is also a mixed system of several legal measures of protection in general and in special laws. As an alternative to guardianship for adults, there is the prolongation of parental rights and obligations.

Parents, spouses, the Center for Social Work or the Public Prosecutor are entitled to initiate the procedure of legal incapacitation. People with intellectual disability are involved in the court procedure mainly through representation by their parents. In most cases the court consults legal experts. Procedural costs have to be covered by the applicant.

Family Members, voluntary citizens, professional from the Center for Social Work can be appointed as guardians. The Center for Social Work selects, appoints and controls the guardians. There is no limitation for disabled people to carry out everyday activities. There is a possibility of official complaint and proposition to change a guardian.

The remaining rights to self-determination of people with intellectual disability depend on the different level of incapacitation. People with severe disabilities have no right to marry and in the majority of cases no right to vote: Only a few cases of sterilization with consent given by a guardian are known in Slovenia.

The national association Sožitje and some services have started to provide training for people with intellectual disability – assertive training, groups of self-advocates, etc. An easy-to-read manual has been published.

The National Program of Social Welfare until the year 2005 has a focus on the development of a higher level of individual rights. NGOs are active in cooperating in a process of changing legislation and changes are expected in the first place in the field of legal incapacitation or guardianship, including the abolishment of the institution of extended parental rights and obligations.

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## 2.2 Conclusions

Adequate laws in the area of capacity and consent are of fundamental importance particularly in relation to adults with intellectual disability and those to whom they have dealings with in many areas of law. For adults with intellectual disability it means recognizing their individual rights to self determination. It also signifies a move away from treating the person who lacks capacity within an old-fashioned care-model, based solely on medical diagnosis. Reports from countries show outdated, traditional patterns of incapacitation, but even countries which already had law reforms in this area show remarkable differences as well as gaps between written laws and their implementation into practice.

Despite increasing awareness of the importance of this subject, which sooner or later can become an issue for virtually every family, it still receives inadequate attention in legal education as well as in the field of qualifying court staff, voluntary guardians, family members and other professional staff in the social field. For Professionals and others it is also about recognizing that it is another person's life they are dealing with. Someone who has own individual choices and preferences, and individual rights.

The legislation must respond to the needs to ensure that adults with intellectual disability have as much control as possible in the decisions that affect their lives.

Another reason why reform in a number of countries is regarded as necessary is that at present there is an increasing emphasis on the human rights model of disability.

When present laws on capacity and/or the way they are implemented are examined against the backdrop of the human rights-based model of "inclusion within the society" we begin to see their inadequacies.

### 3. The Right to Services and Support

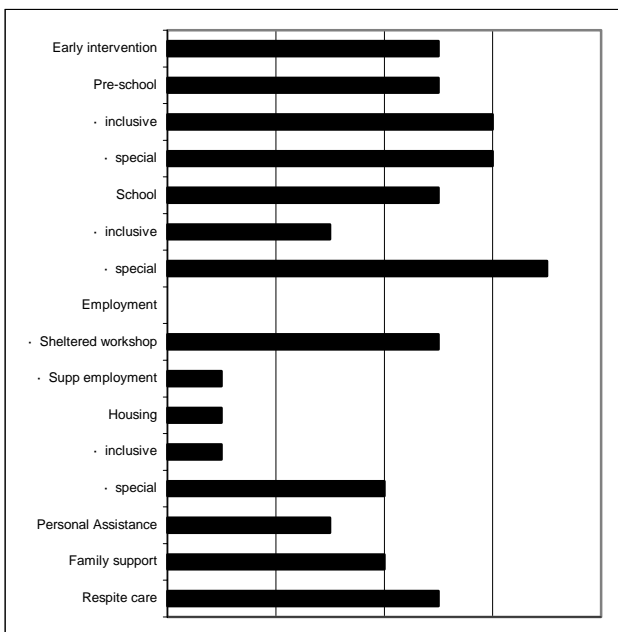
The questionnaire distributed to selected member societies of Inclusion Europe contained a section about the right to services and support for people with intellectual disability. This group of citizens depends to a large extent on support services in different areas of life.

However, the situation regarding the right to services and their availability differs greatly in the European Union. While there is a well developed and for the user reliable system of rights to services in some member states, in other countries the availability of services depends on the financial situation of the state or system that pays for the services.

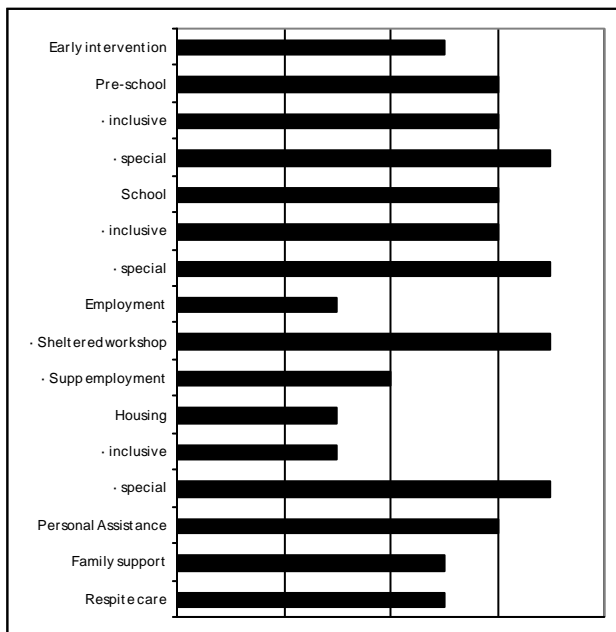
The availability of services differs greatly between Member States and accession countries (although Slovenia has the same level of service availability as Spain and Belgium), but also regarding the type of services. Graphic 1 indicates that the availability of places in the special, segregating systems of special schools, sheltered workshops and special housing is relatively high, whereas not nearly enough inclusive services are available. However, it is very positive that the availability of inclusive pre-school services is high, as is respite care and family support.

In terms of the legal right to these services (Graphic 2), the right to specialized services in the areas of pre-school, school, sheltered employment and living facilities is assured in most of the countries, although it depends often on a prior assessment of the needs of the specific person. However, when this is compared with the question if these rights are legally enforceable, the situation looks quite different. Only in the area of school education every country indicated that the right to school education is enforceable by law. In the other areas of services, waiting lists or limited budgets often result in the situation that a disabled person cannot actually claim his or her right.

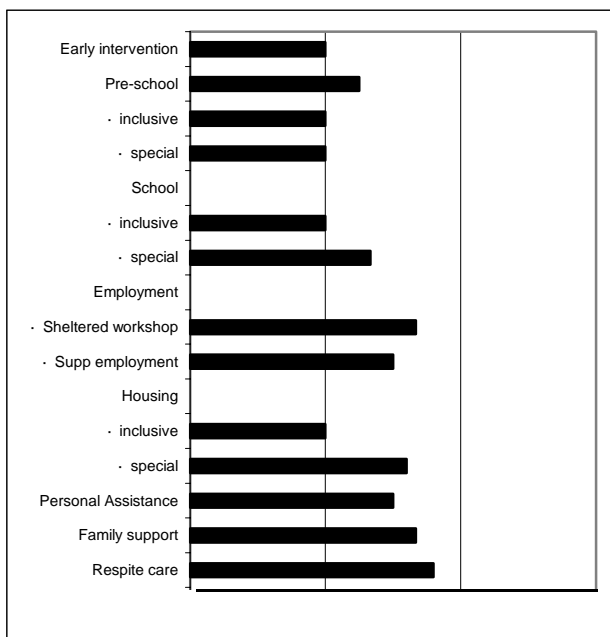
Except for school education, people with intellectual disability in the studied countries have to apply for many of their support services. Costs for basic services are usually paid by the state, however, personal assistance, family support and respite care often must be paid to a high percentage by the disabled person. The disabled person usually has also to contribute to the costs for inclusive or special housing, mostly depending on the income situation.



**Graphic 1**  
At least 80% of necessary places available.



**Graphic 2**  
Legal right to services.



**Graphic 3**  
Satisfaction with legal situation.

Graphic 3 shows the satisfaction level of the national member organisations of Inclusion Europe with the legal situation of access to services on a scale from 0 = not acceptable to 3 = excellent. It is obvious that the satisfaction with the legal situation is generally quite low. This applies especially to pre-schools, inclusive schools and inclusive housing. Surprising are the comparatively good marks for respite care and family support. It is possible that this is due to the fact that these relatively new services have been legislated relatively recently and therefore have more modern legislation.

As is also confirmed by the following country report, the situation regarding the access to services is quite different in the member states of the European Union and needs improvement to ensure that every disabled person has real access to the services this person needs.

### 3.1 Country Reports

#### **Spain: Users cannot choose services according to their quality**

Lack of economic resources prevents persons with intellectual disability irrespective of their legal capacity from freely choosing their life style as they have to adapt to low levels of funding which limit their personal expression. Specific subsidies and pensions exist for individuals based on contributions and basic pensions. At institutional level, there are agreements between institutions and the Government of each Autonomous Community. The right to services is governed by general legislation as well as by specific regulations for each Autonomous Community depending on how it organizes its social services.

Services in Spain are guaranteed, but not to the extent that consumers can choose according to service quality. There are federations and associations that work to improve service quality and access to services. In the case of legal incapacitation, the guardian guarantees the person's right as a consumer to receive the quality services required.

Coordination of services provided on a different legal basis is not always ensured, however, agreements exist in some cases. Inclusion, non-discrimination and equal participation of people with intellectual disability in services are promoted but not guaranteed. They depend on the goodwill of workers in public and private services.

#### **Sweden: The social welfare system**

People with disabilities must have the same chance as others to participate in community life. Responsible for achieving this is society as a whole, but ultimately the state, local municipalities and county councils. This is regulated in legislation such as "The Social Service Act" and in the "Act Concerning Support and Service for Persons with certain Functional Impairments". Despite this legislation, many disabled persons do not yet receive the support they are entitled to by law.

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All citizens of Sweden can be said to be protected from poverty by the social welfare system. Everybody has a right to a minimum income. Persons with intellectual disability have an additional protection. The protection is based on a national index of what a disabled person should have left after all expenses for food, health care, housing, transports, etc. have been paid.

The right to services is governed both by general legislation, which applies to all citizens, and by special legislation, which applies to a defined group of people, e.g. people with disability. Special and general legislation are co-ordinated in a way that general legislation applies to everybody, but if there is specific legislation, applicable for example to persons with disability, the latter goes first because this is perceived as the most beneficial to persons with disability.

Consumer rights are protected in Sweden through a governmental agency. There is also legislation to protect consumer rights. In the legislation for the administrative organisation it is clearly stated that all information and the environment should be accessible to all. There is, with the exception of legislation concerning the working life, no specific legislation regarding non-discrimination or inclusion.

### **Poland: Disabled people cannot afford services**

Only the poorest sections of the Polish population have the right to free services, all others must pay. However, most people cannot afford this and therefore do not use services for disabled people. In general there are very few services in Poland, mostly because of lack of funds.

Persons with intellectual disability are not protected from poverty in any special way. Their social benefits are on the level of the social minimum. There is a differentiation between integrated and institutional settings: integrated settings are in general provided by NGO's where people with intellectual disability receive support for integration in normal life. The institutional settings still work in the old fashioned system of total care, thus stopping all integration. There is no coordination of services provided on a different legal basis.

Users must find the necessary information about services themselves. In general, the information on rights, services and their quality is bad. There are very few services and there is almost no choice for the users. However, they can complain about the quality of services to the authorities.

The service system also does not ensure inclusion, non-discrimination and equal participation of people with intellectual disability in society. The system is very small, inflexible and only seldom provides support for inclusion and independence.

### **Germany: Many laws impair coordination of services**

The most important rights regarding services for disabled people, like housing, vocational training and work (sheltered workshops), and social support are governed by the Bundessozialhilfegesetz (BSHG). Besides, there is a confusing variety of Social Laws which specifically cover health care, personal care, support on the labour market, as well as other disability benefits.

Since January 2003, there is a right to protection from poverty according to the new law "Grundsicherungsgesetz". It entitles to the payment of a cash allowance to cover a person's basic needs. If the person lives individually, additional payments for the rent are possible, depending on the personal financial situation. Free transportation, tax benefits, etc. are also possible.

Although the law (§3a Bundessozialhilfegesetz) is ranking community-based support higher than institutionalized support, the regulations provide an "advantage" for the institutionalized services:

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- a disabled person who wants to move from a group home into a community-based setting, must pay a higher share for the support than in the group home: The "protected" income is only 539,- EUR (§ 79 BSHG) compared to 808,- EUR if support is provided in a group home.
  - Cost contributions by parents of disabled persons for the support in an institution are limited to 26,- EUR per month, but this limit does not apply for community-based support, where parents have to pay for the support if they exceed certain limits of income/assets.

Coordination of services and protection of consumers should be ensured by the Social Code Nine (SGB IX), which came into force on 1 July 2001 and provides for the introduction of "Joint Service Centers" in a combined effort of all public authorities responsible for social support. Counseling as well as quick and non-bureaucratic decisions for the benefit of the disabled citizen are the goal. However, the implementation so far does not really work. The implementation of other basically positive steps included in that law is partly blocked by specific (financial) interests of public welfare and/or social insurance authorities.

The quality of services is ensured by various regulations covering, for example, living facilities, service providers, or personal care. However, there is still need for improvement.

In many cases, there are difficulties finding out which public agency is responsible for a specific support. Often they have conflicting interests, resulting in unacceptable delays. The SGB IX is meant to bring about improvements. At present, however, it is too early for a judgement of its efficiency. The variety of responsibilities for services between the national, state, regional and local level may lead to a diversification of support standards not always for the benefit of the users.

Germany is in the process of a broad anti-discrimination-legislation, which has started with a constitutional clause "Nobody shall be disadvantaged because of a disability". In 2002, the federal "Behindertengleichstellungsgesetz" (BGG - Disability Equal Rights Law) was passed, which mainly provides "accessibility" for disabled people. However, this federal law is binding only for federal (national) bodies and nationwide companies (e.g. the German Railway).

The already mentioned SGB IX was proclaimed as a "change of paradigms" from the "disabled person as an object of public care" towards a "citizen with full right to participation in society" in the field of social rights.

At times of increasing public overall expenditures and lack of state budgets, attempts to save money in the system of Social Welfare and Services are inevitable in order to prevent the system from "collapsing". However, recently authorities have started a number of budget-orientated, uncoordinated measures – some of them obviously unlawful if put into practice – to reduce public spending. These attempts are likely to put at risk the achieved standards of services for people with intellectual disability and their families.

These developments are contrary to what the federal government has described as the "change of paradigms" within the latest disability legislation, which is described above. The current economical strain with the high unemployment rates and its enormous costs and losses must be regarded as a serious threat against the future progress in striving for full inclusion of people with intellectual disability in all areas of society.

### **France: "Unique desks" should ensure coordination of services**

In theory, the French service system aspires to ensure integration, non-discrimination and equal participation of people with intellectual disability in the society. However, these objectives are often not achieved in practice. People with intellectual disability do not benefit from individual protection against poverty. They can benefit from the general system for the prevention of poverty.

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The orientation law for disabled people (n° 75-534 of 30 June 1975) establishes a legal framework specific to disabled people. The law on modernisation of social and medico-social services of 2 January 2002, although applicable to social and medico-social services for disabled people, is applicable to other types of services as well. Other laws govern the right to specific services.

The right to accessible information about services is not ensured in consideration of the specific needs of people with intellectual disability. The law of 2 January 2002 establishes a legal framework for the quality of the services and the protection of the service users.

There is no coordination of services provided on a different legal basis. UNAPEI considers it indispensable to simplify the steps necessary for disabled people or their families to claim their rights. It supports, therefore, the idea of a speaker or of a unique desk which would coordinate on behalf of concerned people all the necessary services. In addition, UNAPEI requests that the reform of the Orientation Law is the occasion to work for equal treatment throughout France.

The same simplification and clarification can be achieved by these "unique desks" for disabled people or their families in the area of moderation in the relations between the managers of services as well as social and medico-social services and the administrative supervisory authorities.

### **Belgium: Bad regional distribution of services limits choices**

In view of the lack of places in services in Belgium, as well as their bad geographical distribution, people with intellectual disability in practice have no choices of support services. They are obliged to take the service which offers them a place.

Regional laws govern the right to services: in Flanders, the relevant authority is the Flemish Fund, in the Wallonie it is the Walloon Agency for the Integration of Disabled People, in Brussels it is the COCOF (French-speaking), the COCON (Flemish-speaking) and the COCOM (bi-community). These various bodies deal with disabled people living in their region, approve and subsidise the services located in their territory. They also control the service quality and coordinate the available services. However, there is no coordination at national level.

The rights of the consumers of services are currently not defined from a legal point of view. There are no laws specific to people with intellectual disability, they benefit from the same rights as everyone. Nevertheless, because of the distribution of specialised services as well as the lack of places, disabled people have in practice never the possibility to choose a specific service.

There is no obligation to provide information accessible to people with intellectual disability. The existing accessible information is based on individual initiatives. Regarding their protection as consumers, disabled people enjoy no special protection apart from that of any other citizen.

Disabled people are entitled to an income replacement allowance if they do not have paid employment, as well as to an integration allowance which varies according to the degree of disability. When the person is living in an institution, a third party reduces its integration allowance. The income replacement allowance is calculated in relation to his/her family situation. The integration allowance is calculated according to the degree of the person's autonomy.

### **The Netherlands: Personal budgets can leave disabled people in a weak position**

The protection of people with intellectual disability from poverty in the Netherlands is fairly weak. Compared with other citizens they almost always have the lowest income and often live at or under the poverty line. In services, persons with intellectual disability pay part of the costs, but al-

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ways keep a little amount of money for clothing and leisure. Persons with intellectual disability living independently have the same allowance and pay nothing or a little of the costs, depending on their income/allowance. But for inclusive and integrated living and participation the low income often is a problem. This makes social inclusion limited and poverty is a constant threat.

Social security is not sufficient, the rights are diffuse because of local differences resulting from a decentralised policy. There is also a lack of accessibility and a lack of information. Extra costs resulting from a disability are not fully covered.

Regarding the right to care services, a decision of a specific administrative body is always necessary to determine if the person with intellectual disability actually is entitled to this right, in which form the service should be provided, and under which conditions. The rights are enforceable as far as there is a possibility to appeal, but in practice there are difficulties. Also there are often waiting lists: theoretically there is a right to a service, but it cannot always be realized, because of waiting lists. However, there is a legal limit to waiting lists and waiting time.

Children are obliged to follow education. But for children with severe disability it is often decided that they are not able to learn and therefore there is no obligation for them. In 2003, the right is introduced to go to a regular school with allowances for the child. This is a kind of personal budget, but not completely enforceable since schools have possibilities to escape the obligation.

There is not general right to employment, but after an assessment there is a right for people with intellectual disability to sheltered employment.

There is very little accessible information about services for people with intellectual disability. There is the freedom to choose a service, but in practice this is limited because there is not enough capacity: waiting lists and monopolies of large 'conglomerated' institutions and care providers limit the right to choose. The government increasingly leaves matters to the stakeholders: care providers, insurance companies and people with intellectual disability. In this field the people with intellectual disability are by far the weakest party. There is also a law on the Quality of Care, which is in practice not very useful for persons with intellectual disability. This law aims for self-regulation of care-providers, without sufficient monitoring and sanctions.

People with intellectual disability have the legal right to file complaints regarding care services. In practice, the complaint bodies are often not independent and parents of persons with intellectual disability often feel intimidated or fear negative effects on the care of their child. Parents who use complaint procedures often feel unprotected. When a complaint body decides that the complaint is justified, the service provider is not even obliged to take measures and often the service does not change.

The Ministry of Health is in practice the mostly active body in cases of serious accidents or bad conditions in care services, but this is not sufficient when quality of care is structurally low.

The coordination of services that are provided on a different legal basis is not ensured. In practice, the personal assistant, parents, or - with some luck - a service provider or an institution takes care of this coordination. Coordination of services is often a problem, especially when persons with intellectual disability live integrated in society. An increasing number of different services are delivered by different persons or providers, thus leading to patchwork care.

The service system does little to ensure inclusion, non-discrimination and equal participation of people with intellectual disability in society. There is a general trend to de-institutionalisation, but there often is a lack of social infrastructure and equal participation. This means that possibilities for inclusion are limited. There is only very limited accessibility of employment, transport, education and information.



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There is a tendency to change from specific rights with limited but concrete care provisions to a global and abstract right to services. This can open flexible possibilities, but can also cause differences at the operational level as well as legal insecurity and inequality. Besides, the rights and the conditions to admission to the rights can be rather easily altered by the government.

The policy is changing towards a more demand-centered approach. This can give a lot of possibilities and flexibility, but persons with intellectual disability are very much the weak party.

For persons with intellectual disability with complex problems there is often not enough money available to provide good care, in institutions there are often large groups and not enough staff. This is also a problem when persons with intellectual disability have a personal budget, because this budget is often too low to cater for complex needs.

### **Slovenia: More services, more providers, more choices**

There is a National Plan against poverty in Slovenia which does not differentiate between levels of material protection for different groups of citizens. However, there are big differences between people with intellectual disability living in institutions and those who live at home. While addressing concrete questions about providing services for people with intellectual disability, there is a process of privatisation and pluralisation of different services. In addition to services provided by the state, there are increasingly NGOs and private service providers.

The right to services is determined by the level of disability. There is more and more available information for parents and disabled people, more rights to choose and there are big differences in the quality of services. The coordination of services is a huge problem in Slovenia, mostly because there is a large number of different legal provisions which are covered by many government departments.

Slovenia presently prepares to pass a law on equal participation disabled people which should be decided upon in 2004.

## **3.2 Conclusions**

The situation of service provision for people with intellectual disability in the European Union and the accession countries continues to raise concerns. It is unacceptable that the quality and the extend of service provision depends on where a person lives in the Union or even within a member state. The practice to exclude children with severe and profound disability from education violates their basic human rights and must be banned.

Two issues in service provision are particularly concerning: Firstly, the basically positive move to more and more person-oriented services seems to leave people with intellectual disability in a difficult position. They have to negotiate directly with the service provider and they have to coordinate themselves a range of different services. It is crucial to establish reliable and independent counseling services for the users to strengthen them in this situation.

Secondly, it is alarming that most of the respondents have expressed their feeling that the service system in their country is not geared to ensure inclusion, non-discrimination and equal participation of disabled people. This is supported by the fact that very few service providers have prepared accessible information about their work. We have to conclude that most services in Europe are still provided in segregating settings which do not support the empowerment of the user. It will be crucial to ensure in the future that more services have the full inclusion of people with intellectual disability into society as their objective.

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## 4. Access to Rights and Justice

The access to rights and justice is generally one of the most difficult issues for persons with intellectual disability, mainly because the justice system is not really accessible to them in most, if not all, European countries. Even non-disabled citizens often have difficulties following and understanding legal procedures. This is even more the case for people with intellectual disability who need much help and support in this area.

The following country reports show that the basic problems are very similar in all responding EU and accession countries and that in some countries already some steps have been taken to remedy the situation in order to give persons with intellectual disability the same access to rights and justice as all other citizens.

### 4.1 Country Reports

#### **Spain: Many people with intellectual disability are found in jails**

In Spain, once legal incapacity has been declared, access to justice is guaranteed as it is for other citizens through the incapable person's legal representative, for any type of proceeding. In administrative or judicial proceedings, access is gained with the help of social workers, support staff or family members who contact the Public Prosecution. In police and criminal proceedings the person gets the help of the guardian or the Public Prosecution.

It is important to remark that both NGOs or one or more family members may be appointed guardians of the ward in which case they have full legal representation to defend the ward's rights. Whether acting as guardians or not, the right for NGOs to act in Prisons is guaranteed by the Prison Regulations which provide that the Prison Administration should promote collaboration with associations and institutions for the purpose of social reintegration. More specifically and in addition to action within centres, such associations are able to co-manage action programmes outside prisons (for training or treatment) or in residential units (for 3<sup>rd</sup> degree prisoners). Family participation is provided for by communications and exit permits which, especially in Forensic Psychiatric Hospitals, are considered essential tools for applying treatments.

The legal procedure system in Spain is a general system for everyone. By providing evidence based on a medical report with expert or forensic medical evidence, attenuating circumstances may be considered

Regarding people with intellectual disability in prison or penitentiary institutions, FEAPS has a national programme for social integration and rehabilitation activities under the penitentiary system. In 2002, 14 associations / federations took part in this national project which provided assistance to 290 people with intellectual disability.

At national level, there is a study by the government (BOCG; Senado, Series I from 8<sup>th</sup> November 2002) about the situation of people disability in Spanish prisons. The results: 306 cases of intellectual disability were found, representing 45,8% of the prison population with disabilities.

Related to alternatives to court procedures, mediation or reconciliation exist as alternatives and all citizens have access to them irrespective of whether they are legally incompetent or subject to the care of a guardian. Some persons gain access to mediation by exerting their full capacity, while others do so through their legal representative. Problems arise for persons who are legally incompetent but have not been legally incapacitated because they are unable to understand the effects of their actions. Mediation has recently begun to be used successfully.

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Regarding accessibility there are typical problems for persons with intellectual disability:

- It is difficult for them to understand documents and in some cases such persons are totally or partially illiterate. However, legal language is also difficult for the general public to understand.
- Access to courts for people with a physical disability.
- Persons with sensory disabilities need the support of a third person for all procedures.

In general, persons with intellectual disability are unable to gain access to the legal system with full understanding and capacity for resolving problems unless they receive external assistance.

Regarding the cost of the procedures, in Spain the State funds a legal aid scheme. This provides lawyers who offer defense work for accused persons who cannot afford a private lawyer. The public network of Social Services must provide the necessary documents to be provided prior to and during any court case – in this case, the Official Certificate of Disability, social reports if appropriate, etc. Any costs shall be paid as stated in the Sentence, irrespective of any disability.

The professionals related with the access to justice, like lawyers, judges, police, legal guardians etc., are generally not trained in dealing with persons with intellectual disability except for any particular personal or professional experience they may have had. Usually the guardians are the only people who understand the extend of such persons' difficulties and needs (guardianship entities, families, etc.)

### **Sweden: Lack of training and awareness of legal professionals**

The right to access to justice does not differ for people with intellectual disability compared with other people. There is a general lack in knowledge about intellectual disability in the court and the police authorities. This constitutes a problem when e.g. the police questions crime victims with an intellectual disability.

Swedish NGOs or family members have no legal right to participate in civil or social rights procedures. In the criminal law system a contact person can be appointed. The social services have the right to conduct investigations and initiate social rights procedures.

The welfare policy is a basic element in the structure of Swedish society, whose ambition is for financial security and social rights to be guaranteed to all citizens. This general system also benefits people with functional impairments and the basis of this policy is a tax system in which all taxpayers contribute, for the good of all, according to capacity, and in which funds are distributed with the objective of leveling out differences in peoples living conditions, according to the principle of an egalitarian society.

Legislation on the rights of people with functional impairments is characterised by the ambition to integrate issues in the context to which they belong, e.g. in legislation concerning education, the work environment or social services. Specific legislation is created only in special circumstances. The Disability Act, in force from 1994, is very much a human rights statute. Help provided under the terms of this Act is free of charge. The Act supersedes previous legislation in this area and extended the rights of people with functional impairments.

As an alternatives to court procedures, mediation can be an alternative in company law matters. In some areas, e.g. school legislation, a complaint or an appeal will be investigated by governmental authorities instead of the court. The government bears the cost of the procedures in administrative court. The plaintiffs bear the cost of legal representation when representation is not appointed by the court. In civil cases the plaintiffs almost always bear the cost of legal represen-

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tation. Legal aid can be provided in some legal areas, if the home insurance (with a liability insurance) does not cover the expenses and if the plaintiff's income is very low.

In general terms, there is a huge accessibility problem for persons with intellectual disability in the Swedish legal system according to the special needs required by the impairment. The training level of those professionals related to the justice system, like lawyers, legal guardians, administration staff, police and judges, about people with intellectual disability and their requirements is extremely low. When such a professional possesses appropriate knowledge, this is often due to a personal interest that emanates from personal life experiences.

### **Poland: Pressure for legal incapacitation of disabled people**

There are no special regulations regarding counseling, legal support and representation for people with intellectual disability in the Polish legal system. All special counseling is provided by NGO's, but it is not efficient and incidental.

In Polish administrative and court procedures there are no special regulations which help persons with intellectual disability. In most cases the court and administrative officers try to persuade to legally incapacitate the person for the sake of simplification of the procedure (which is obviously unlawful). The only special regulation protecting the rights of disabled people in court is the obligation of attendance of public prosecution in legal incapacitation procedures.

A person with intellectual disability can ask for a public attorney during the penal procedure as any other Polish citizen, and he will receive it on the same basis. In civil law, NGOs and social services have the right to represent the person on whose behalf they work.

In civil law, anyone who has a legal interest in winning the process for one of the sides can join the procedure on that side. NGOs, family members and social services can use this regulation for supporting people with intellectual disability in court, but they must prove their legal interest. Spouses, parents, siblings, descendents and adopted persons can become representatives of a person with intellectual disability.

In criminal procedure, the NGO can appoint its representative to become a participant in the procedure if it is necessary to protect the social interest or very important individual interests. That interest must be defined as statutory for that NGO, specifically it can be the protection of freedoms and human rights.

There are no procedures which are adjusted to specific needs of intellectually disabled persons. Some of possible adjustment are:

- NGOs, specified by the Polish Ministry of Justice, can sue on behalf of citizens in cases of consumer protection and alimental rights. NGOs who work on consumer protection, environmental protection or invention protection can join the civil procedure.  
Necessary changes: NGOs working for disabled people should have the right to sue on their behalf and to support the person with intellectual disability in court.
- There is the obligation that a person in criminal procedure must have an attorney if that person is deaf or blind or mute.  
Necessary changes: Also persons with intellectual disability should have that obligatory right.
- Necessary general change: In every court and administrative procedure there should be the possibility for a supporter/assistant for a person with intellectual disability.

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As alternatives to procedures in civil courts, a conciliation can be done before the initiation of a process in every civil case where the substance allows for it. The court rejects the conciliation in cases where the conciliation is unlawful, act contrary to the rules of social coexistence or damages the rightful interest of one of the sides. Conciliation is initiated by a professional judge in local court. Every contract can include a mediation clause. On that clause the contracting parties can try to solve the problem with a mediator before they go to court. The decision made by such mediation can be approved by court and thereafter have the power of a court decision.

The documents are very difficult, the language is incomprehensible even for professionals. The administrative procedures are complicated and not clear, accessible information for participants is not efficient. Regarding physical accessibility and orientation it is important that despite the obligation to made all public offices accessible to persons with disabilities, the courts are not adjusted to the needs of disabled people. Appeal and complaints procedures are also complicated and unclear, however, it helps that an appeal must be written by a professional lawyer.

In general the costs of legal procedures are covered by the different parties. If a person is unable to cover the costs of procedure the court can reduce the obligation of covering the costs or release the person from that obligation. The reasons vary in different procedures. NGOs as well as organisations without legal identity can be released from the obligation of covering the costs if they proof that are unable to cover them.

There is a very important lack regarding the training of legal professionals about people with intellectual disability and their requirements. The training level of legal administrative staff, police, judges, etc. is very poor and in most cases non-existent. The knowledge of lawyers mostly is based on stereotypes.

### **Germany: New laws allow NGOs to represent disabled people in court**

In Germany, State Agencies and Public Social Insurance Offices are obliged to counsel every citizen who asks for support; however, the confusing diversity of the German social system and is specialised authorities, who occasionally try to refuse the support of an applicant rather than support him or (if responsibility for support is refused) send him to another (allegedly) responsible office, as well as arguments between authorities about the responsibility to cover a specific need are barriers which are still there. The regulation for “Joint Service Centers” in the Social Code (SGB) therefore is an important step for change, but has not had the expected effect so far.

Specific offers to counsel people with intellectual disability and their families are mainly limited to NGOs like Lebenshilfe with its local and regional associations. Access to court procedures is mainly provided through their assistance in co-operation with a number of skilled lawyers who are interested in this legal field.

There are no specific rules for the support of people with intellectual disability in police or criminal court procedures. Assisting persons can be admitted to hearings and other procedural steps, but it is important that flexible support – mainly provided by NGOs, service providers or family members – is in place at the right time. Regulations for a cost-free defense in certain kind of criminal procedures apply to people with intellectual disability to the same extend as for all other citizens.

During 2001 and 2002, there have been some remarkable law reforms in Germany to improve equal rights and access to justice for people with disabilities:

- The “Behindertengleichstellungsgesetz” (Equality Law for Disabled People - BGG) contains specific regulations (§§ 12, 13 BGG) in favour of NGOs for a kind of “class action” against disadvantages of disabled people within the scope of this law.

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- The Social Code SGB IX contains a regulation (§ 63 SGB IX) which entitles an NGO to claim a disabled person's right (the disabled person must agree) in a court procedure.
  - New regulations in the "Sozialgerichtsgesetz" (SGG) and in the "Verwaltungsgerichtsordnung" (VWGO) entitle employees of NGOs – not necessarily lawyers – to support and represent disabled people in procedures at Social Courts (Health and Personal Care, Pension, Unemployment and Disability Benefits Cases) and at Courts for Administrative Law (Social Welfare Cases (BSHG), e. g. Housing Support, Social Welfare Allowances).

In the criminal law system, there are no special rights concerning the support of disabled people. If a person with intellectual disability is accused of having committed a crime, police and State Attorney have the possibility to involve family members or other third persons – for example experienced service staff – in interview proceedings.

Expert certificates are ordered to assist the Court in deciding whether an offender with intellectual disability is capable of being guilty in the sense of criminal law. If so, "normal" imprisonment is possible, if "limited capability" (in the sense of criminal law) is certified, a reduced imprisonment is possible; if no capability to be guilty of the committed crime is certified, a person can be put in a forensic psychiatric hospital. The public authorities in Germany have no statistics that differentiate between various indicators of disability/psychiatric illness etc. in order to know how many people with intellectual disability are in prison or penitentiary institutions

Regarding the alternatives to court procedures, the options are:

1. Negotiation with State agencies / social insurance staff in order to convince them of the legal right for a specific need;
2. Administrative procedure of complaint ("Widerspruchsverfahren")
3. Court procedure

The BGG is considered as a major step to improve accessibility of legal procedures, for example it contains the right to a sign language interpreter. Anti-discrimination legislation on State level and in the field of Civil Rights must follow - draft bills have already been introduced. A problem is always the gap between written law and its implementation.

In relation to the training of legal professionals, there are only few lawyers with specific knowledge available. The legal guardians have generally good knowledge, volunteers are partly skilled. The legal administration staff has generally a good specific, task-related know-how, but a poor overall knowledge of disability. The relevant skills of the police are generally poor. Judges, with the exception of guardianship judges, have also a poor knowledge about people with intellectual disability. Except for lawyers and guardians, there are no specific offers for training staff in these areas about intellectual disability

### **France: Juridical assistance improves access to rights and justice**

The "Houses of Justice and Rights" and "Juridical Assistance" offer legal assistance. Some specific actions are dedicated to disabled people through sessions called "sessions for vulnerable people" assisting elderly people, disabled people or people under judicial protection.

The "houses of justice and rights" have three main objectives:

- access to justice;
- conciliation;
- proximity legal assistance.

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The “Juridical Assistance” in conformity with the law of 10<sup>th</sup> July 1991 is a single bureau based in each High Court of Justice (Tribunal de Grande Instance). Assistance is offered considering the revenues of the person. No special treatment is offered to disabled people for assistance.

Regarding the participation of NGOs, article 2-8 of the French penal procedure code states that all associations legally registered for at least 5 years and whose interior statutes state their ability to participate in civil or social rights procedures, can do so for disabled people for a list of discriminations described in article 225-2 and 432-7 (e.g. employment) of the French penal code when these discriminations are based on the health condition of the person or his or her disability. The NGOs must nevertheless receive authorisation from the victim, the family or guardian.

Except the system of guardianship, no specific procedure is provided for disabled people. The law of 2<sup>nd</sup> January 2002 renovating social and medico-social action kept the principle of a qualified person to help service users to exercise their rights. Recourse to this qualified person is subject to the inability of the service user to exercise his or her rights.

Regarding accessibility, there are no specific documents available for people with intellectual disability. Administrative or complaint procedures are complex and not simplified, making rights very difficult to exercise. Physical accessibility is also generally difficult, despite declarations of intentions by competent authorities. The “Houses of Justice and rights” concentrate their efforts on the existence of help desks.

The level of training of legal professionals in issues related to intellectual disability is very low and most of the time non-existent. The national association UNAPEI offers training sessions to guardians.

### **Belgium: Very few documents and procedures are accessible**

Disabled people have the right to receive, like anyone else, assistance from a so called “prodeo” lawyer. For penal matters, judges will favour the internment of the disabled offender in a psychiatric hospital instead of a prison.

Families, social services, etc. can help disabled people in administrative procedures for social matters, but if the person is not under legal protection he or she will have to sign the documents. When the person is competent to sign, the communal mayor will validate the document. Regarding accessibility of documents there is a strong recommendation for all administration to simplify at least one document to make it accessible to people with different kinds of disability.

It is difficult to give statistics on people with intellectual disability in prison. They are judged regarding their level of responsibility and not regarding their disability. Some people are sometimes not recognised as disabled people, especially people with mild intellectual disability. Convicted disabled people are placed in social defence houses or closed sections of psychiatric hospitals.

Regarding accessibility, very few documents are accessible and people with intellectual disability often need assistance to complete forms. Administrative procedures are complicated and people with intellectual disability need assistance. A project in the Walloon region is placing an indication at the entrance of every public building notifying its accessibility level. ANAHM drew attention to the fact that orientation matters should also be taken into consideration.

Appeal and complaint procedures are also complex and the person needs assistance in the proceedings. The plaintiffs bear the cost of the procedure. Free legal assistance (“prodeo” lawyer) is possible on evidence of small revenues. This applies to any citizen. Regarding the level of training, there is no compulsory training for legal professionals on disability issues.

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## **The Netherlands: Without assistance the access to justice is very limited**

The access to social rights in administrative or court procedures is not specifically organised, but access is related to legal incapacitation. In general people with intellectual disability have access to justice, but in all forms of guardianship the permission of the guardian is required. Only in matters against the guardian, the person with intellectual disability is capable. In practice the guardian plays an assisting role. For people with low income, there is a right to legal aid, paid by the government.

The access to rights in police and criminal court procedures is also not specifically organised. All persons receive legal aid, in case of low income this is paid by the government.

Family members are often appointed as guardians. NGOs can provide advice, counseling or support, but not in a formal role. Social services can give support, but not in a formal role either. They can be asked by the judge to give a report.

Judges are often not sufficiently capable to communicate with people with intellectual disability. They have no special expertise with intellectual disability.

Persons with borderline intellectual disability can be found in prisons only incidentally. Probably 100 – 200 persons with intellectual disability can be found in forensic psychiatric hospitals but there are no exact figures available. This is often in a special part of a forensic psychiatric hospital, or sometimes in a special part of an institution for people with intellectual disability, mostly in cases of sexual violence, violence or psychiatric problems. Other penitentiary institutions exist for minors with borderline intellectual disability who frequently stay in youth penitentiary institutions. This is often in combination with social problems.

For people with intellectual disability without assistance the accessibility of the justice system is in fact very limited. All documents are difficult to read. Complaint and appeal procedures are also not easy to understand. It should also be possible to start a complaint or appeal in a verbal way. Only the police is sometimes trained about people with intellectual disability and a handful of judges.

## **Slovenia: Participation of NGOs and families is very important**

Access to social rights in administrative or court procedures is organised with the help of parents or legal guardians. The national parents association Sožitje offers twice a week a legal counseling. For civil and social rights procedures, the participation of NGOs and families is very important.

For criminal cases, Sožitje do not have any experience and in the last 20 years met only one case, which was solved with help of Sožitje National Association and a professional lawyer. It is not known how many people with intellectual disability are in prison or in other penitentiary institutions.

The main accessibility problems in the Slovenian legal system are:

- Changes of legislation are taking more time than necessary;
- Many administrative procedures are too long;
- Often there are no executive acts, even a few months after a general law passed;
- Appeal and complaints procedures sometimes take a long time, they are solving problems too slow and are too much concerned with administrative procedures.
- There are no appropriate provisions to cover legal costs.



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- There is no training for professionals involved in the legal system. Sožitje has some experiences with training police departments at local level, but this was an exception.

## 4.2 Conclusions

From the reports from different European countries, it is obvious that the access of people with intellectual disability to rights and justice is by no means guaranteed. In fact, the legal structures and proceedings are generally not accessible for them and their legal representation is not very well organised. The general legal framework applies to them regardless of their specific physical, intellectual or financial needs.

The condition of intellectual disability must be taken into account from the beginning of any judicial process. This would help to provide the necessary support and would help the judges and lawyers to offer alternatives to prison or to re-orientate the judicial process.

Not in all countries have disability NGOs the right to defend the interests of people with intellectual disability in courts or administrative procedures. These organisations are, however, generally the most knowledgeable, both about the rights of disabled people and about the needs and abilities of specific persons.

One large problem area is the inaccessibility of legal information. There is very little evidence of easy-to-read information accessible for people with intellectual disability. To provide more documents in accessible simple language would certainly not only benefit people with intellectual disability, but also the general public.

In the moment that a person with intellectual disability is engaged in a legal procedure, all the relevant documents should be in easy-to-read format. The court should provide the necessary support (e.g. social workers) in order to guarantee that the person and his family understand what is going on and support them during the process.

The other key issue is the lack of training and education of legal and administrative staff and the police on issues related to people with intellectual disability and their needs. In none of the countries such a training is being undertaken systematically, either in the framework of the professional training of legal staff or as further education courses. Since attitudes, preconceptions and lacking knowledge prove to be the main barriers for people with intellectual disability for their full inclusion in the life of society, the training of legal and administrative professionals is a very important issue to improve the access to rights and justice for this group of citizens.

There is also a significant lack of knowledge on the situation of people with intellectual disability in prison. Except for Spain, there are no statistics available on the number of people with intellectual disability in prisons or other penitentiary structures. Because of the difficulties in adequate legal representation of people with intellectual disability, this gives reason for concern. Governments and disability organisations should pay more attention to this specific problem. A study about the situation of people with intellectual disability in prison would help to realise that these cases exist and would help to make the governments and courts aware about the lack of support and needs of this group of people.

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## 5. Conclusions and Recommendations

The information collection and analysis undertaken in this project clearly shows that there is a completely different situation regarding legal incapacitation and guardianship laws in all European countries. All organisations of people with intellectual disability and their families have expressed that they consider the existing legislation in their countries as being far from satisfactory. Furthermore, there are in all countries enormous contradictions between the legal situation and its practical application for people with intellectual disability.

It is obvious that persons who are denied their legal capacity and identity are in grave danger of social exclusion and have not even the basic possibilities to fight against it.

The access to rights and justice by people with intellectual disability is therefore the second main issue identified by this project. Our research shows clearly that people who have low literacy skills and difficulties to understand complex legal language have very limited access to justice and very limited possibilities to claim their legal rights. This is especially true for people living in institutions which tend to exclude their residents from society.

Partial or complete legal incapacitation combined with limited access to justice are the ingredients for a degree of social exclusion experienced by only few other groups of people. It is therefore an urgent issue, both in the EU as well as in the accession countries, to create opportunities and new legislation that lives up to the various declarations on human rights adopted by the European Union and its member countries.

While focusing on people with intellectual disability, the implications of this project are much larger: legal incapacitation is also an issue experienced for example by older people, and present legal structures hinder the access to justice for many people who have a lower school education or reduced literacy skills. Improvements benefiting people with intellectual disability will therefore result in improvements for a much larger group of people.

We therefore propose the following actions to improve the situation:

- At the level of **policy and legislation** to develop a White Book on Legal Incapacitation and Access to Rights for people with intellectual disability, containing European minimum standards and recommendations. The White Book could be a basis for national campaigns for a more adequate legislation and policy on this issue.
- At the level of the **training of legal professionals and the public administration** to develop a European Training Package, comprising a general (European) component and a national component designed to inform legal professionals, legal students and staff of the public administration about measures to improve the access to rights and justice for people with intellectual disability.
- At the level of the **training and information of people with intellectual disability and their families** it is necessary to inform them both about their existing rights and situation regarding legal incapacitation and guardianship as well as about the European minimum standards developed in the White Book.

These measures would contribute to a better understanding and awareness of the structures of social exclusion of people with intellectual disability and provide at the same time a basis for action at European and national level to fight against poverty and social exclusion of this group of European citizens.

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# Inclusion Europe

## The European Association of Societies of Persons with Intellectual Disability and their Families

Inclusion Europe is a non-profit organisation. We campaign for the rights and interests of people with intellectual disability and their families. Our members are national organisations from 33 countries in Europe.

People with intellectual disability are citizens of their country. They have an equal right to be included in society, whatever the level of their disability. They want rights, not favours.

People with intellectual disability have many gifts and abilities. They also have special needs. They need a choice of services to support their needs.

Inclusion Europe focuses on three main policy areas:

- Human Rights for people with intellectual disability
- Inclusion in society
- Non-discrimination

Inclusion Europe co-ordinates activities in many European countries, including projects, conferences, working groups and exchange meetings. It responds to European political proposals and provides information about the needs of people with intellectual disability. Inclusion Europe advises the European Commission and members of the European Parliament on disability issues.

This publication has been developed in the framework of the European project „Justice, Rights and Inclusion for People with Intellectual Disability“. It is available in English, French, German, Spanish, Dutch and Polish. All members of Inclusion Europe and especially the following partners have contributed to the success of the project:

- Union Nationale des Associations de Parents et Amis de Personnes Handicapées Mentales (UNAPEI), France
- Conseil Départemental de l'Aide Juridique de Paris, France
- Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung, Germany
- Federatie van Ouderverenigingen (FvO), The Netherlands
- Polish Association for Persons with Mental Handicap
- The Office of the Commissioner for Civil Rights Protection, Poland
- Confederación Española de Organizaciones en favor de las Personas con Discapacidad Intelectual (FEAPS), Spain
- Department of Social Work and Social Services, University of Alicante, Spain



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