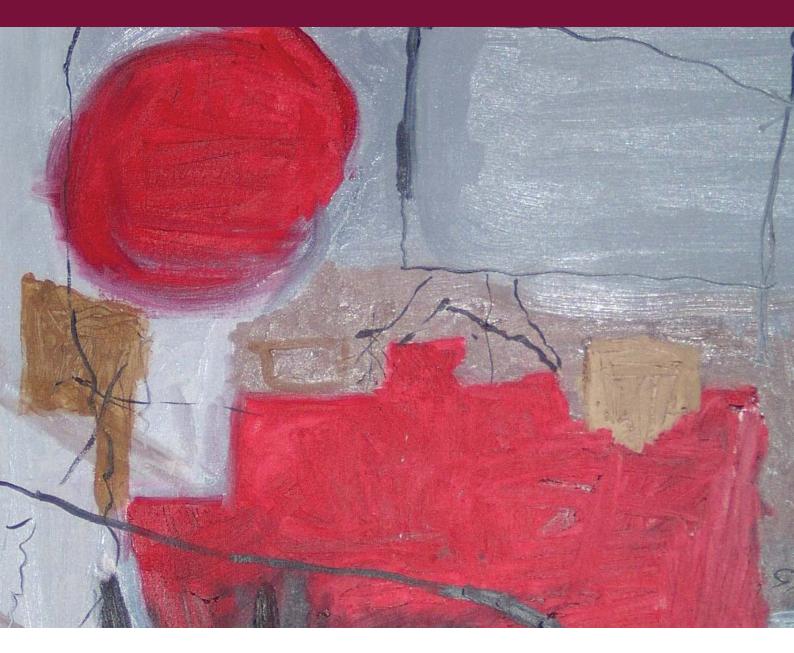
# Equal Rights for all !

Access to rights and justice for people with intellectual disabilities





Report

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# Foreword

Most people with intellectual disabilities in Europe cannot fully participate in the normal life of society. They experience social exclusion and discrimination and often cannot enjoy the rights and benefits of full citizenship. A recent study<sup>1</sup> of Inclusion Europe also proves that they are often victims of poverty and have a very low rate of employment, even when compared to other groups of disabled people.

The European Union and its Member States will therefore not succeed in the fight against poverty and social exclusion in Europe if policies and practices do not promote the active inclusion of people with intellectual disabilities in all areas of life. Equal access to rights and justice must be one of the cornerstones of such a strategy.

Co-financed by the European Commission, the partners of the project "Justice, Rights and Inclusion for People with Intellectual Disabilities" have examined and developed strategies that can support the better inclusion of people with intellectual disabilities in society and promote their access to rights and justice. The project has also developed Resource Materials<sup>2</sup> and training seminars in all project countries and languages in order to disseminate its results.

One of the core problems for people with intellectual disabilities in exercising their full citizens' rights is connected to the issue of legal capacity. For many years, the response of the legal system to people with intellectual disabilities has been the full legal incapacitation through which a person is deprived of the possibility to take legally valid decisions. Substitute decision-making by appointed guardians was – and still is in some countries – the rule, thus depriving the persons concerned of all citizens' rights.

During the last decades, international and European human rights instruments led the way to reforms in guardianship laws, in order to promote autonomy and dignity of persons with intellectual disabilities. Guardianship laws were modernised and now often include the principle of the maximum preservation of legal capacity, judges limiting decision-making powers only in those areas of life considered as most difficult for the individual concerned.

Within the framework of the development of a legally binding UN Convention on the Rights and Dignity of Persons with Disabilities, a crucial new discussion started during the project period. Leading legal experts and disability activists highlighted the contradiction of demanding full citizenship for people with intellectual disabilities on the one hand, and denying them full legal capacity on the other. They advocated for the principle of full legal capacity for everybody, and the right to the necessary support in decision-making. This principle is presently enshrined in the draft UN Convention, but continues to be debated by the United Nations.

Apart from the fundamental issue of legal capacity, access to rights and justice is determined by the general accessibility of administrative and legal procedures. The second part of this publication addresses this very important aspect and makes concrete proposals for positive action and reasonable accommodations. One possible consequence of insufficient

<sup>&</sup>lt;sup>1</sup> Inclusion Europe: Poverty and Intellectual Disability in Europe. Brussels, 2005.

<sup>&</sup>lt;sup>2</sup> Available from Inclusion Europe in English, French, German, Czech, Dutch, Polish and Spanish language.

accessibility and lack of adequate support can be seen in the fact that in many European countries a significant number of people with intellectual disabilities is serving prison sentences, even though in many cases they were not able to understand their wrongdoing when they committed the act.

The most important actors in improving access to rights and justice are the judges who trial the petitions, the lawyers who represent the interested parties, and the staff of administrations who decide about access to citizens' rights. However, these parties are not the ones who lead law and administrative reforms. These are the human rights and disability NGO's, self-advocates, politicians and academics. We believe that a change in the culture and attitude of the protagonists is essential. They must be convinced of the necessity of reforms and be informed about the needs and abilities of people with intellectual disabilities.

Unfortunately, there is still a significant gap between legislative reforms and the attitudes of closely involved actors and of the society in general. It is our wish that this document, apart from highlighting the principles that have been recommended, sheds light on the measures that national administrations and legal systems should embrace in order to increase the autonomy of persons with intellectual disabilities and to respect their dignity as equal human beings.

**Françoise Jan** President Inclusion Europe

# **Executive Summary**

People with intellectual disabilities enjoy the same human rights as all other persons. They are entitled to live, work and participate in the community, take their own decisions and manage their own lives to the greatest extent possible. Detailed discussions with member societies of Inclusion Europe, as well as additional research carried out in the framework of this project have demonstrated that people with intellectual disabilities have difficulties in access to rights and justice in all EU Member States and accession countries.

In some cases, adults with intellectual disabilities cannot fully understand the nature of legally binding transactions or decisions, or comprehend their consequences and effects. Legal instruments for formal legal incapacitation, full or partial legal representation (guardianship) or assistance to exercise the right to self-determination are far from being harmonized in the 25 EU-Member States. This may result in totally different standards of support and protection for persons with intellectual disabilities throughout the European Union in the context of decision-making and exercising full citizenship.

In this document, the partners of the project "Justice, Rights and Inclusion for People with Intellectual Disabilities" have outlined some principles that cover the most important aspects of legal capacity, legal assistance, legal protection and representation of adults with intellectual disabilities. We believe that the law should recognize an adult's right to autonomy and self-determination. Legal representation should not be imposed simply because a person takes a decision that other people do not understand or agree with. In addition, a measure of legal representation should not be established for an adult with intellectual disabilities, as long as the adult can exercise his/her rights with adequate advocacy and assistance for decision-making. Where such a measure is necessary, it should be proportional to the individual circumstances and the needs of the person concerned.

Unfortunately, the absence of advocacy structures to facilitate personal decision-making of adults with intellectual disabilities may result in extensive use of measures of partial or full legal incapacitation prior to the appointment of substitute decision-makers, who could take over the task to organize the social support needed by the person concerned. The development of effective support and community care services is substantial to avoid unnecessary infringements to the legal status of persons with intellectual disabilities. It is important that the services offered to persons with intellectual disabilities reflect the broad range of their needs and are offered in the community.

In addition, the legislative framework should recognise that the assessment of the legal competence of a person must not depend only on a medical diagnosis of an intellectual disability, but take into account that a person's ability to act on his own behalf may vary from time to time, depending on the difficulty of the affairs in question, the availability of advocacy services for personal and supported decision-making or other factors. A demand for legal representation should only be considered when there is clear evidence for the necessity to adopt this measure in order to protect the person concerned, as a result of a fair court procedure. The person concerned must be informed promptly in a language, or by other means, which he or she understands, and must be heard in person by the judge responsible for the procedure. Adequate support during the proceedings must be available free or at affordable costs. However, such a measure should not automatically deprive adults with

intellectual disabilities of the right to marry, to make a will, to vote, to consent to or to refuse any intervention in the health field, or to take other decisions of personal character.

Legal assistants and legal representatives, who must respect the wishes of the person concerned as much as possible, should be liable, in accordance with national laws, for any loss or damage caused by them to adults with intellectual disabilities while exercising their duties. Adequate structures for their supervision should be developed and implemented.

Equal access to rights and justice is fundamental in order to reduce poverty and social exclusion and to strengthen democratic governance. Meaningful access to rights and justice requires that justice and administrative systems accommodate those who are disadvantaged. It is also closely linked to poverty reduction since poor and marginalized people are often also deprived of choices, opportunities, access to basic resources, and of a voice in decision-making. Lack of access to justice limits participation, transparency and accountability.

Like all citizens, people with intellectual disabilities are entitled to enjoy all services provided by the states. To ensure an effective access, governements must refer to the general principles of mainstreaming, non-discrimination and universal accessibility and should implement minimum standards in the fields of public administration and access to justice. An effective policy for the access to justice and rights by people with intellectual disabilities must be adopted in co-operation with different stakeholders.

The project "Justice, Rights and Inclusion for People with Intellectual Disabilities" has identified some basic standards and general principles that should be fundamental for improving access to administrative and legal systems. Public administrations should develop and implement quality plans to assure equality of opportunities to citizens with a disability. They should include in those plans quality indicators and good practice guidance. Some form of certificate of good governance in the field of disability should be adopted.

Inclusion Europe strongly supports administrative reforms that aim at simplifying administrative procedures and processes. In addition, personal support for all citizens with difficulties in reading, writing and understanding must be available at every level of public administration. People with intellectual disabilities should receive this support whenever necessary, free of charge and without having to make any special request or file an application. A single point of contact could contribute to the simplification of procedures and avoid the duplication of formalities as well as possible contradictions.

Legal awareness is fundamental for the access to justice of persons with intellectual disabilities and governmental as well as non-governmental actors should undertake strategies to promote it. In addition, legal aid schemes should be available and made known to people with intellectual disabilities, which should include both financial and social support.

Unfortunately, the limited literacy and intellectual skills of people with intellectual disabilities has led to the fact that across Europe a significant number of them serve sentences in normal prisons. This can be seen as the ultimate consequence of lacking access to rights and justice and this publication proposes some concrete measures to deal with this problem.

# 1. Legal Assistance and Representation

#### 1.1 Introduction

Persons with intellectual disabilities enjoy, by virtue of the respect due to their human dignity and integrity, the same human rights, in equal measure, as all other persons. As such, they are entitled to live, work and participate in the community in the same way as everybody else. They are entitled to make their own decisions, which is a basic human right, and it is vital to their further development that they are encouraged to deal with their own affairs and manage their own lives to the greatest extent possible.

In everyday life it can be the case that an adult, due to his or her intellectual disability, cannot understand the nature of a legally binding transaction or decision or indeed comprehend its consequences and effects. Transactions or decisions by a person with intellectual disability maybe regarded as legally invalid, depending on the provisions relating to legal capacity in the legal system of EU member states.

Legal instruments governing formal legal incapacitation, full or partial legal representation (guardianship) or assistance to exercise the right to self-determination are far from being harmonized in the 25 EU member states. This may result in totally different standards of support and protection for persons with intellectual disabilities throughout the EU in the context of decision-making and exercising full citizenship.

Traditional court measures covering legal incapacitation are a strong restriction of the personal rights of a person and can lead to a situation where people lose the chance to exercise any form of self-determination. This can make them very vulnerable to social exclusion, abuse or exploitation. The transfer of civil rights to others with inadequate or only formal judicial control opens up the possibility of overuse or misconduct of the power of legal representation.

Inclusion Europe and its member associations have developed standards in the field of legislation for legal assistance and representation in favour of adult people with intellectual disabilities. This should serve as a benchmark for all EU Member States considering legislative measures to improve the legal situation for individual citizens with equal rights as members of society. Our specific concern is to raise awareness of the need for adequate laws to provide a balance between the rights of people with intellectual disabilities to have their private decision-making autonomy respected and at the same time to have measures in place which provide legal protection where necessary.

The principles set up in this publication have been developed with reference to a prominent international document: The Recommendation No. R (99) 4 of the Committee of Ministers of the *Council of Europe* of 23<sup>rd</sup> February 1999 on *Principles Concerning The Legal Protection Of Incapable Adults.* This framework provides a high degree of credibility.

Furthermore, Inclusion Europe draws on the work of the United Nations on a Draft Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. The responsible Ad-Hoc-Committee of the UN regards the issue of equality before the law and legal capacity, including questions of selfdetermination, as a topic of high importance. The draft version of Article 9 of the UN Convention clearly underlines the priority for assistance for people with intellectual disabilities, enabling them to exercise their personal rights before any legal measures of legal incapacitation arise or substitute decision-making processes take effect. Adequate communication and procedural safeguards are mentioned as other core elements of the draft. Inclusion Europe strongly supports this modern approach to safeguard equality, dignity and personal freedom of people with intellectual disabilities to the highest possible degree.

Inclusion Europe identified as a key issue the demand for a clear definition of *legal capacity*. Some countries may interpret legal capacity as juridical capacity or "the right to have rights". There should be no question that an intellectual disability in any jurisdiction of a EU Member State cannot justify the denial of equal human rights of any citizen. In the context of this Project the term *legal capacity* is used in the sense of "the capacity to act" – on the basis of equal legal status – on one's own behalf.

According to our view, full or partial legal incapacitation as an isolated, formal act of a court should not be a legal option since it discriminates against people and takes away their right to decide for themselves; the appointment of a legal assistant or representative does not necessarily have to be connected with a parallel withdrawal of rights from the person with an intellectual disability.

Not only within the enlarged European Union of 25 Member States, but also on the international level, in general, there is a growing body of people moving from one country to another, often remaining for long periods. In this context, Inclusion Europe calls for the necessary international agreements to avoid conflicts if citizens are not in a position to exercise their rights while they are outside the jurisdiction of their home country. For this purpose, the *Hague Conference on Private International Law* has worked out a *Convention on The International Protection of Adults (2000)*, which is still due to be ratified by all Member States of the European Union. Agreement on the proposed provisions should be taken forward.

The national governments of EU Member States are asked to take into account the specific interests and demands of adults with intellectual disabilities as one of the main target groups of vulnerable people affected by legislation on legal capacity and legal representation. Thus, Inclusion Europe is recommending the adoption of the standards and general principles as outlined below, which are also applicable to other forms of disabilities.

#### **1.2 Basic Standards and General Principles**

In the following chapters, the project partners set out to describe our vision for basic standards and general principles for legal capacity and decision-making of people with intellectual disabilities.

#### Scope of application – Respect for Human Rights

The principles outlined in this paper are meant to cover all aspects of legal capacity, legal assistance, legal protection and legal representation of adults who, by reason of an intellectual disability, are unable or have limited ability to make, communicate and/or act upon personal decisions concerning any or all of their personal or economic affairs, and consequently are at risk of exclusion or exploitation within such decision-making processes. The law should recognize an adult's right to autonomy and self-determination as well as the fact that people have the right to make their own decisions. Legal representation should not be imposed simply because a person makes a decision that other people do not understand or agree with.

The laws, procedures and practices relating to the legal support and protection of adults with intellectual disabilities should be based on respect for the dignity of every human being, their human rights and fundamental freedoms. Legislative and practical initiatives with an impact on the rights of persons with intellectual disabilities must include the broadest possible consultation with the community of persons with intellectual disabilities and their representative associations.

# <u>Clear distinction between "recognition as a person before the law" and "legal capacity"</u>

Inclusion Europe calls on all EU Member States to guarantee and safeguard equal legal status for citizens who have an intellectual disability to the same extent as for all other citizens. The right to "recognition as a person before the law" is guaranteed to all human beings as a basic human right through Article 16 of the *International Covenant of Civil and Political Rights* (ICCPR). This legal status endows each individual with the capacity to be recognised as a person in the legal order, providing "juridical personhood" (or "juridical personality"; in French: *personalité juridique*; in German: *Rechtsfähigkeit*) with the capability to be a potential holder of rights and obligations (e. g. the right to inherit, the right to property, the right to receive social benefits) from the moment of birth until the death of each human being. It cannot be subject to any limitation by the State and is a necessary prerequisite to all other rights.

Consequently, the term "legal capacity" entails the capacity to exercise these rights and to undertake these duties by way of one's own conduct. "Legal capacity" logically presupposes "juridical personhood", the capability to be a potential holder of rights and obligations. Other than "juridical personhood", the "legal capacity" as the capacity and power to engage in a particular undertaking or transaction, in general to create, maintain or close legal relationships, may depend on the possession of additional requirements, for example reaching the age of majority (18 years in the majority of jurisdictions) as a precondition for capacity in a number of legal circumstances.

This distinction should be clearly recognised by all EU Member States. Applying a – false – definition of legal capacity as "the ability to have rights", thus ignoring the unquestionable human right of "juridical personhood", would result in a partial or complete exclusion of people with intellectual disabilities from community life and be discriminatory.

Both "juridical personhood" and "legal capacity" are important to people with intellectual disabilities; together they constitute the foundation of their status as human beings with equal rights, including the right to self-determination.

Member States must acknowledge equality before the law of all people with intellectual disabilities, and provide measures to enable them to exercise their rights in cases where support is needed, in order to promote equal opportunities and access to rights and justice for everybody, and to prevent exclusion and discrimination.

#### Subsidiarity, necessity and proportionality

No measure of legal protection has to be established for an adult with intellectual disabilities unless the measure is necessary, taking into account the individual circumstances and the needs of the person concerned. A measure of legal representation is not necessary, as long as the adult can exercise his/her rights without the nomination of a legal representative, but with adequate advocacy and assistance for decision-making.

The framework of social and legal support should include structures to facilitate and enable adults with intellectual disabilities to take decisions about their personal and/or financial affairs personally to the maximum extent (supported decision-making).

Where a measure of legal assistance or legal representation for an adult with intellectual disability is necessary, it should be proportional to the individual circumstances and the needs of the person concerned.

In many jurisdictions, measures like the private "power of attorney" are promoted in order to avoid court proceedings for legal support and representation of people with difficulties in decision-making. Wherever this is the case, the legal system should provide sufficient control of the actions taken by these private representatives where the person concerned is no longer – due to disability, sickness or age - able to provide this control personally. However, it must be recognised that a private "power of attorney" is not an option for the majority of adults with intellectual disabilities who have never been able to set up this legal instrument properly. For them an efficient support system of assistance and legal representation is of utmost importance.

#### Importance of an overall concept for social support and legal protection

The better an overall local or regional infrastructure for the provision of the individually needed social support and assistance for the adult with an intellectual disability is developed

and in place, including advocacy and assistance in the decision-making process when making an assessment for individualized funding of social services (e.g. housing and/or vocational training and support), the more likely it is to prevent a formal measure of legal protection and representation.

The absence of advocacy structures to facilitate personal decision-making of adults with intellectual disabilities may result in extensive use of measures of partial or full incapacitation prior to the appointment of substitute decision-makers who take over the task to organize the social support needed by the person concerned. This may result in excessive involvement of juridical measures and resources, possibly with disregard of the principles of subsidiarity and necessity as described above.

The development of effective support and community care services should be substantial to avoid unnecessary infringements to the legal status of persons with intellectual disabilities. It is important that the services offered to persons with intellectual disabilities reflect the broad range of their needs and are offered in the community. Assistance regarding the enjoyment of fundamental rights, such as access to education, employment, adequate housing, leisure activities and certain civil and political rights encouraging greater social participation, ought to be promoted through the provision of multi-disciplinary support.

The interdependence between the overall support system for people with intellectual disabilities and the legal context of access to justice and the promotion of self-determination as the main focus of this Project has to be taken into account whenever reform of structures of traditional guardianship-measures is under discussion.

#### Maximum preservation of capacity

The legislative framework should recognise that the assessment of competency of a person must not depend only on a medical diagnosis of an intellectual disability, but also take into account that a person's ability to act on his/her own behalf may vary from time to time, depending on the difficulty of the affairs in question, the availability of advocacy services for personal and supported decision-making or other forms of support, which could help avoid questioning the legal capacity of an adult at all.

Accordingly, consideration should be given to the inclusion of measures without the precondition of any formal act of legal incapacity, but with the arrangement of legal assistance or representation to undertake a specific act or acts in a area while acknowledging the legal integrity and the (remaining) capability of the person concerned at the same time. This could be achieved simply by assessing the need for legal assistance or representation in a specific area of decisions without raising the question of general incapacity of the person concerned.

Consequently, a measure of legal assistance and representation for an adult with intellectual disability should not result automatically in a complete or partial removal of legal capacity.

#### **Good Practice**

As an example, the German reform of guardianship-legislation, the "Betreuungsgesetz" (BtG) of 1992, entitles an adult, who cannot handle specific legal transactions due to an intellectual disability, to the appointment of a "Betreuer", a new type of legal assistant (§ 1896 BGB – Civil Code). The procedural investigation of the guardianship court is focused on the disability-related need for support with legal transactions, whereas the legal capacity of the person concerned is not questioned under the BtG. The prior task of the "Betreuer" is to enhance and support self-determination of the person concerned, while he/she at the same time becomes entitled by the guardianship court to take decisions on behalf of the person concerned within his/her scope of authorization with the obligation to consult with the person concerned before any act of legal representation is exercised in important issues (§ 1901 BGB). At the same time, the person with intellectual disability principally keeps his/her capacity to make decisions without requiring authorization by a third party, whenever practically possible.

A request for legal representation should only be considered when there is clear evidence, as a result of a fair court procedure, of the necessity to protect the person concerned. Consideration should be given to the assessment of the need for support of the person in specific areas of legal affairs instead of complete legal incapacitation, as still found in the legal system of many countries.

In particular, a measure of legal assistance or representation should not automatically deprive the person concerned of the right to marry, to make a will, to vote, or to consent or refuse consent to any intervention in the health field, or to make other decisions of a personal character at any time when his or her capacity – together with adequate support - permits him or her to do so.

Even where a measure of legal assistance or representation has proved necessary, the adult with intellectual disability should remain able to enter into legally effective transactions of an everyday nature whenever possible.

#### Fair and effective procedure

The list of those entitled to apply for measures of legal assistance or representation for an adult with intellectual disability should be sufficiently wide to ensure that such measures can be considered in all cases where they are necessary. Given the definition of a measure of assistance and support to exercise equal rights, it does not seem to make sense anymore if national laws leave the right to apply and the leading role in the procedure with the public prosecutor, characterizing the measure rather like a public investigation and intervention close to the field of penal law, with an attitude of rather protecting the legal order than supporting self-determination of people with disabilities.

The person concerned should be informed promptly in a language, or by other means, which he or she understands, unless such information would cause a severe danger to the health of the person concerned. In any case, close family members, for example the parents of an adult with intellectual disability, should be informed about any procedure which deals with questions of legal capacity, legal assistance or legal representation. They should have the right to submit their opinions and experiences to the court.

No measure of legal assistance or representation which interferes with the legal capacity of an adult with intellectual disability or results in the appointment of a legal representative should be taken unless the authority responsible for such a decision has personally seen and interviewed the person concerned and received an up-to-date report from at least one suitably qualified expert about the adult's condition. The expert's certificate should be based not only on medical diagnosis, but also take into consideration the life-situation of the person concerned and comment on possibilities of supported decision-making as the least restrictive intervention.

Adequate support of the adult concerned during the proceedings must be available free or at an affordable cost, as an alternative to the private engagement of a lawyer at the person's own expenses. The person concerned should have the right to be heard in person, preferably by the judge entitled to hear the case. In some jurisdictions, the law provides for a personal interview preferably at the disabled person's home instead of a hearing at the Court House. It is suggested to recognize this option for decision-making authorities as a way to better understand the life situation and the personal needs of the person concerned.

Everybody who is the subject of a legal procedure dealing with the appointment of legal assistance or representation should have adequate rights of appeal once the judgment has been made known to him/her. The law should provide that personal wishes, opinions and appeals expressed by adults with intellectual disabilities must be regarded by authorities as legally valid interventions of the person concerned.

The results of the investigation and assessment should be communicated to the person concerned appropriately. Proper assistance and interpretation should be provided in order to make both the procedure and decision itself understandable for the adult with intellectual disabilities to the highest possible degree.

Measures of legal assistance and representation for an adult with intellectual disability should be of limited duration and subject to periodical review. Laws should provide flexibility for the termination of such measures if the conditions for them are no longer fulfilled. In particular, regulations should allow tailor-made alterations of such measures in cases where a change of circumstances or a change in the adult's condition arises.

#### **Good Practice**

For example, the German "Betreuungsgesetz" allows the appointment of a "Betreuer" for a maximum of seven years – the court is obliged to decide about the termination, alteration or prolongation of a "Betreuung" before the end of the duration of the measure which had been fixed in the original decision.

The choice of a legal assistant or representative should follow the wishes of the person concerned unless there is evidence that this would not be in the best interest of the person,

especially due to a possible conflict of interest. If there is no personal choice of legal assistant or representative by the adult with intellectual disability, the appointment of a close family member should preferably be considered. Any person chosen to become a legal assistant or representative must be suitably qualified.

In most countries with traditional or modernised guardianship-systems in place, volunteers are regarded as the first choice for appointment as legal representatives, and parents of adults with intellectual disabilities in a number of jurisdictions form the majority of volunteers together with close family members who act as representatives for people unable to exercise their rights due to age or illness. But for most parents of adults with intellectual disabilities it is a major concern as to who shall safeguard the legal interests of their disabled family member after they are no longer able to do so. Thus, the search for citizens who are willing to act as volunteers in the important field of legal support and representation, as well as their training, is an important task which has to be recognised.

When necessary, the court or public authority in charge of these measures may appoint a professional support-service, provided there is evidence that, due to the complexity and/or difficulty of the legal affairs of an adult with intellectual disability, such an arrangement is in the best interest of the person concerned.

The appointment of a public authority to act as legal representative of a person with intellectual disability should only be a matter of last resort.

There should be adequate regulations to provide for provisional measures of legal protection, support and representation in cases of emergency.

#### The role of legal assistants and representatives

The law should facilitate the courts to tailor the powers and duties of legal assistants and legal representatives to the level of support the person concerned needs. For the legal assistant or legal representative the interests and the welfare of the person concerned must be of the highest consideration when exercising his tasks. The ultimate goal of the legal measure should be to facilitate a self-determined life of the person concerned to the maximum degree.

Consideration should be given to call on legal assistants and legal representatives to present to the court a "plan" as to how support and assistance for a person in need of a legal assistant or legal representative should be provided.

Prior to making important decisions for an adult with intellectual disability, the legal assistant/legal representative should consult and communicate in an adequate way to find out and respect the wishes of the person concerned. Past wishes of the person concerned should be ascertained as far as possible, be taken into account and given due respect.

Legal assistants and representatives must carry out their tasks in a way which ensures that personal support instead of purely administering legal affairs of the person concerned is achieved. This must entail having personal contact, in order to be properly informed about the actual situation and everyday living conditions of the person and trying to find out about his/her needs and wishes for improvement and/or rehabilitation.

Legal assistants and legal representatives should be obliged to give the court notice about changes of conditions, which would allow the termination, or limitation of the measure of legal support and protection.

#### Health care interventions

Where an adult, even if subject to a measure of legal protection, is in fact capable of giving free and informed consent to an intervention of health care, this intervention may only be carried out with his or her consent. If an adult is, in fact, incapable of giving free and informed consent to a health care intervention, the intervention may be carried out only if it is for the direct benefit of the person concerned and if authorization has been given by his or her representative or by an authority or a person or body provided for by law.

Consideration should be given to the designation by the law of appropriate authorities, persons or bodies for the purpose of authorizing healthcare interventions of different types, when adults who are incapable of expressing free and informed consent do not have an assistant or representative with appropriate powers. Consideration should also be given to the need to provide for the authorization of a court or other competent body in the case of certain serious types of interventions. Special rules may be provided by national law in relation to interventions which, because of their special nature, require the provision of additional protection for the person concerned (e. g. Sterilization).

When, because of an emergency situation, the appropriate consent or authorization cannot be obtained, any necessary medical intervention may be carried out immediately for the benefit of the health of the person concerned.

#### Liability and control

Legal assistants and legal representatives should be liable, in accordance with national law, for any loss or damage caused by them to adults with intellectual disabilities while exercising their functions. In particular, the laws on liability for wrongful acts, negligence or maltreatment should apply to legal assistants and legal representatives involved in the affairs of adults with intellectual disabilities. In order to minimize the risks for legal assistants and legal representatives, sufficient offers for insurance should be in place. For volunteers, such safeguards should be financed by the state in order to protect them from any additional financial burden.

Adequate structures for the control of legal assistants and legal representatives should be developed and implemented. The legal system of each EU member state should provide a monitoring system concerning the work of professional and voluntary legal assistants and legal representatives.

Consideration should be given to the implementation of adequate planning and assessment processes for appropriate decisions on behalf of the person concerned, especially when the legal affairs of the person concerned require the appointment of a professional legal assistant or legal representative.

Efficient performance of legal representatives must be based on an adequate social infrastructure to facilitate the provision of social support and social benefits for adults with intellectual disabilities.

In particular, States' obligation should extend to the establishment and support of non-profit associations with the function of providing and training voluntary and professional legal assistants and representatives in order to assure the availability of adequate numbers of qualified and motivated persons to carry out the functions to assist and represent adults with intellectual disabilities. Training courses should include information about the rights of the person with intellectual disability, the legal framework of the support system, the rights and duties of the supporter as well as general information about intellectual disability and the relation, in general, between the support person and the person with intellectual disability.

#### **Good Practice**

In some countries, for example Austria ("Sachwaltervereine"), France ("Associations Tutelaires"), Germany ("Betreuungsvereine") and Spain, non-profit associations have, by law, become part of the system of legal support and representation, in order to search, train and counsel volunteers. In addition, these associations may provide professional services when regarded as necessary by the court. With proper support, such organizations can play an important role in favour of person-centred, individual support for adults with intellectual disabilities.

#### Current inadequacies and shortcomings in EU Member States

The work on this project enabled Inclusion Europe and its Member Organizations to identify inadequacies of the law within the legal systems of EU Member States involved, especially:

- legislative gaps in the field of legal capacity and decision-making;
- the absence of development and implementation structures for supported decisionmaking for people with intellectual disabilities, as the prior alternative to any measure of legal incapacitation and representation;
- urgent need for modernisation of old-fashioned laws on formal incapacitation and full guardianship which are not in accordance with the principle of the least restrictive alternative when a measure of legal protection is to be applied;
- deficits in the implementation of existing laws, even if they provide more flexibility than traditional guardianship laws, including procedural shortcomings and cost-barriers;
- lack of awareness that equal human rights, the acknowledgement of an equal legal status of people with intellectual disabilities as persons before the law and the entitlement to the same equal rights as everybody else and the priority of the principle of self-determination which needs to be promoted and protected before any measure of limiting capacity or appointing legal representation is taken into account;
- shortcomings in practice, like too little control and evaluation of the activities of legal assistants/curators/guardians, as well as too little efforts to search for, train and counsel volunteers in the field of legal assistance and representation of people with intellectual disabilities.

The fact that law reforms are under discussion or being carried through in a number of European countries like Austria, England, France, Germany, Ireland, Italy, Scotland and Switzerland can be regarded as an indicator for a growing sensitivity in this important field of safeguarding personal rights and legal protection of people with intellectual disabilities. Therefore, Inclusion Europe regards the catalogue of Minimum Standards and General Principles outlined in this paper as a recommendation occurring at the right time to promote and harmonize the rights of people with intellectual disabilities based on a modern approach, acknowledging the human right of recognition everywhere as equal before the law as well as the right to self-determination to the highest possible degree.

# Suggestions for future developments

The European Union is strongly promoting a change in the way societies approach disability. A Policy in favour of equal human rights and the fight against discrimination characterize the paradigm shift from a traditional, rather medical-based model of regarding disabled people as

pitiful recipients of welfare benefits to a modern, human rights based model of full and equal citizenship.

Full participation in decision-making about personal legal affairs is of vital importance in this context. Prior to adopting old-fashioned forms of degrading people with intellectual disabilities by formally taking away most of their personal rights as a pre-condition for overall substitute decision-making, there should be a meaningful, needs-based support to facilitate self-determination.

Legislation regarding legal capacity and decision-making must reflect individually different needs, must take into consideration the approach of minimum intervention in the lives of people with intellectual disabilities and must be consistent with providing proper care, protection and maximum support to enable them to realise their full potential and make the best use of the abilities they have.

In this context, Inclusion Europe regards it as important to emphasize that assistance in decision-making must encompass complete support, in practice in the form of legal representation. However, a framework for assisted decision-making as the first option differs from a traditional system of substituted decision-making combined with formalized, often inflexible incapacitation in that it does not deprive the individual of legal status as a citizen with equal rights, the capacity to act or the right to exercise legal capacity.

Legislation on the issue of legal capacity, legal assistance and legal representation at national level should therefore reflect the modern approach in general to disability policy which is inherent in the anti-discrimination strategy of EU Policy as well as in the negotiations at the level of the United Nations for a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities.

Consequently, Inclusion Europe has proposed the following text for Article 9 "Equality before the Law" of the UN Convention:

- 1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as a person before the law,
- 2. States Parties shall recognise that persons with disabilities have, and are entitled to exercise and enjoy, legal capacity on an equal basis with others, in all fields,
- 3. States parties shall:
  - a. ensure that persons with disabilities are entitled to use assistance in order to exercise legal capacity, and that such assistance is adequate to meet the person's requirements, promotes the rights of the person, respects the will and preferences of the person, and is free from conflict of interest and undue influence;
  - b. enact legislation and devise suitable procedures to facilitate access to, while preventing abuse of, supported decision-making including periodic review.

As a consequence, any measures of personal representation must take into account the principle of subsidiarity towards the concept of supported-decision-making appropriately, including provision for sufficient safeguards around their use.

These principles raise fundamental questions such as:

- How to provide proper assistance for people with intellectual disabilities to exercise legal capacity?
- How to maintain the balance between the principle of self-determination and the necessary protection of people with intellectual disabilities from disadvantages caused by their own legal transactions or by decisions declared by others on their behalf?

Comparative Projects providing opportunity to exchange both experiences of best practice and experiences with the implementation of modernised legislation may be useful tools to answer such questions and endorse further developments for useful change.

Inclusion Europe is aware of the limited influence the European Commission has in the field of Civil Law, under which legal provisions on legal capacity, legal assistance, representation and protection are usually covered. However, it might be suitable to apply the *Open Method of Coordination* in this field to facilitate change in the sense described by this project, in order to encourage progress for improving and restructuring of legal support for people with intellectual disabilities based on the principles of non-discrimination, equality of opportunities and self-determination.

Inclusion Europe and its Member Associations call on EU Member States to take into consideration the Standards and General Principles described by our project, in order to increase the chances for people with intellectual disabilities to participate in the model of European Citizenship everywhere on an equal basis with everybody else.

# 2. Access to Rights and Justice for People with Intellectual Disabilities

#### 2.1 Introduction

Equal access to rights and justice is fundamental in order to reduce poverty and social exclusion and to strengthen democratic governance. Meaningful access to rights and justice requires that justice and administrative systems accommodate those who are disadvantaged. Access to rights and justice is also closely linked to poverty reduction since poor and marginalized people are often also deprived of choices, opportunities, access to basic resources and of a voice in decision-making. Lack of access to justice limits the effectiveness of poverty reduction and democratic governance programmes by limiting participation, transparency and accountability.

In the field of intellectual disability, there has been a growing awareness and historical development towards equal citizenship and equal rights. The principle of equal opportunities is related to the Normalization Principle defined by authors like Bank-Mikkelsen in 1954. The Normalisation Principle considers the person with intellectual disability as a **subject of rights** (Citizen Principle) who should be able to live in an environment that is as normal as possible (Universal Access Principle). This principle emerged from the movement of human rights and the equality of all persons. Normalization leads to a change in the way of understanding support services: there should be services for everybody and not just for a special group of people.

In the 1980s, the Independent Life Paradigm (De Jong 1979) was outlined, which defends that persons with disabilities themselves should decide about aspects of their own life. It comes back to the concept of citizenship, the person as a subject of rights. It promotes the principle of **self-determination**, in which the attitude of society should be proactive, formative, promoting and not over-protective.

Self-determination, universal access and equal citizenship are the fundamental principles that must guide all efforts towards access to rights and justice for people with intellectual disabilities.

Access to rights is a very broad notion. For people with intellectual disabilities it incorporates equal access to all services available to the citizens as well as access to benefits and to the democratic process. It also can be understood in the context of rights of a person vis-à-vis other citizens - however, in the context of this publication, we will not address this aspect. Access to rights for people with intellectual disabilities is mainly determined by the accessibility of public administrations as the first and foremost point of contact for every citizen.

Accessibility in this context is not limited to physical aspects alone. It comprises also "intellectual accessibility" in terms of being understandable for everybody, as well as the attitudes of the staff working in the administrations in terms of being welcoming and receptive to the special needs of all their clients.

People with intellectual disabilities require special attention by their families, communities and authorities. A number of facilities have to be put in place to enable them to know and

understand their rights, and to be able to enforce them. Knowledge of their rights is frequently low, both by themselves and also by those responsible for their care and services. Information on their rights should be broadly disseminated and greater efforts are required to ensure access of persons with intellectual disabilities to appropriate legal aid.

Access to justice, as a separate but related concept, guarantees that every person has access to an independent and impartial court and the opportunity to receive a fair and just trial when that individual's liberty or property is at stake. Impediments to such access can be numerous: high court costs, restrictive jurisdictional rules, complex regulations, ineffective enforcement mechanisms, and corruption. Access to justice is also linked with judicial independence and legal literacy. It is generally accepted, though, that basic access to the services of a competent lawyer is a major element of access to justice.

Access to justice is, in essence, a question of equality. It is the equal right of the weaker part of society to defend its rights. Among them are people with disabilities who do not enjoy the benefit of the law simply because they do not have access to justice.

Equality does not mean identical treatment. In order to attain true equality before the law, we must acknowledge and be sensitive to the deep social inequalities that exist in relation to people with intellectual disabilities and tailor rules of law and procedures to their needs. Legal systems should use non-identical treatment to attain equality, as there is no greater inequality than the equal treatment of unequal situations.

Access to justice means different things to different people. It could simply mean having a court building within easy reach for persons with physical disability, it could mean having affordable legal representation, and for people with intellectual disabilities it could mean easily understood court proceedings and documents written in easy-to-understand legal language. People who do not know their rights, who cannot obtain the services of a lawyer, who are unaware of whether and how they can have recourse to the law have no way to seek and obtain justice. Equality encompasses both the prevention of discrimination and the amelioration of the conditions of disadvantaged persons.

The project "Justice, Rights and Inclusion for People with Intellectual Disabilities" has identified some basic standards and general principles that should be fundamental for improving access to rights and justice in administrative and legal systems. The following chapters will outline these general principles and then propose and discuss some specific measures that can be taken to improve access to rights and justice for people with intellectual disabilities.

#### 2.2 General Principles and Basic Standards

People with intellectual disabilities are entitled to enjoy all services provided by the State. To ensure effective access, States must refer to the general principles of mainstreaming, non-discrimination and universal accessibility. They should implement minimum standards concerning two main fields: one is the field of public administration in charge of implementing and monitoring the effective enforcement of legislation, of being the recipient of the demands of citizens, and of representing the State. The second is the justice sector, understood as the authority that includes the criminal and the civil justice system.

The general principles of mainstreaming, non-discrimination and universal accessibility lead to a number of basic standards, which are detailed below. Furthermore, authorities should follow some general recommendations to provide effective and efficient measures.

#### Mainstream services for people with disabilities

Access to rights is not something specific to the social sector but must be ensured in all aspects of life, for example in education, leisure or transport. A policy for access to justice and rights by people with intellectual disabilities must be adopted in co-operation with different stakeholders. Clearly, intellectual disability is not a specialist concern, but should be the concern of everybody; for example, all Ministries should include disability aspects in their decisions. The concerns of people with disabilities therefore need to be included in the conception of any programmes from the outset.

#### Basic Standards

The co-ordination of services in the administration should take disability aspects into account. This would contribute to the simplification of procedures and avoid the duplication of formalities and procedures, as well as possible contradictions and overlapping.

Legislative procedures must be developed to co-ordinate social and health assistance. Synergies in relation to resources must be assured. Access to justice is, consequently, much more than improving access to courts, or guaranteeing legal representation. In a human rights-based approach, the citizen should be considered as the essential protagonist and attention should be paid to the following central ideas:

- Placing the citizen at the centre of the public services;
- Responding to the needs of the user;
- Strengthening the social and health systems;
- Changing laws and rules correspondingly;
- Promoting adequate financing and joint responsibility;
- Guaranteeing proximity in management and in provision.

#### Non-discrimination

The non-discrimination principle creates equal treatment and equal opportunities. Its aim is to prevent or limit the effects of discrimination, which often lead to the fact that a person cannot take part fully in the social life of the community. The factors of discrimination may be indirect or direct.

The European Court of Justice held that discrimination can arise through the application of different rules to comparable situations, or the application of the same rule to different situations <sup>3</sup>. In the context of access to rights and justice, the latter often prevails: people with

<sup>&</sup>lt;sup>3</sup> (Case C-243/951 Kathleen Hill and Ann Stapleton v The Revenue Commissioners and Department of Finance [1998], Case C-279/93 Finanzamt Köln-Altstadt v Schumacker [1995] ECR I-225)

intellectual disabilities are treated by administrations or the judicial system like any other citizen and often do not receive the specific help and support they need.

#### **Basic Standards**

To promote a non-discriminatory approach regarding access to rights and justice, measures of positive action need to be adopted by administrations and the judicial system. These measures could include:

- Appointment of a disability Ombudsman at the level of each administration;
- Prohibition of discriminating behaviour;
- Reasonable accommodation for persons with disabilities;
- Ensuring accessibility of all public buildings;
- Provision of easy-to-read information for people with intellectual disabilities.

#### Good Practice

In France, the High Authority to Fight Discrimination and for Equal Opportunities supports people with intellectual disabilities to achieve concrete access to justice by helping them to collect evidence of discriminatory actions. The victims of discrimination receive valuable help to support their case and to choose the appropriate legal procedure.

#### Universal accessibility

Access for everybody, notwithstanding the level of disability, to all common goods and services by taking into account people's specific needs, is extremely important for their inclusion into society. Material and personal support is necessary, enabling the enjoyment of the environment, goods and services in the most autonomous way possible.

#### Basic Standards

To guarantee universal access to rights and justice, special attention should be paid to the specific needs for information and guidance for people with intellectual disabilities.

In many cases, people with intellectual disabilities do not access information in the same way as others do. Their often low literacy skills deny them access to regular information, which hinders equality of rights among citizens. According to the principle of universal accessibility, the environment, processes, goods, products, services, as well as objects, instruments and tools should be understandable, usable and practicable for all persons in safe conditions and in the most autonomous way possible. Therefore, methods of clear, comprehensible and accessible information should be made available. The availability of easy-to-read information would allow people with intellectual disabilities to understand documents or information that could affect them. In this way, access to rights and justice would be improved by an administrative reform and the simplification of all the forms that affect people with intellectual disabilities.

# **Good Practice**

The Spanish Law 51/2.12.2003 on Equality of Opportunities, Non-discrimination and Universal Accessibility for Disabled Persons includes two important strategies: the fight against discrimination and universal accessibility. According to the provisions of this law, important measures against discrimination could be the prohibition of discriminating behaviour, the fulfilment of accessibility requirements, the elimination of obstacles and reasonable accommodation provided to all persons with disabilities.

In relation to accessibility, public administrations should adopt measures prescribing requirements relating to: building accessibility, environment, tools, goods, equipment and products; better conditions relating to access, participation in and use of resources; complementary aids (economic support, communication systems etc); adoption of internal rules which promote and stimulate the elimination of disadvantages or general situations of discrimination of people with intellectual disabilities; human and material resources for the promotion of accessibility and non discrimination.

In order to make accessibility universal, the nearest possible physical proximity between citizens and administrative or legal services should be the objective. Legal services as well as the civil service in general are often regarded as being distant from the daily reality of people. For this reason, physical proximity, as well as proximity in treatment, is important so as to contribute to the idea that these bodies are at the service of the people.

Proximity brings the government nearer to the needs of the people, thus increasing the feedback between the civil service and civilians. This contributes to a stronger democratic participation because it aims at solving problems in an area closer to the citizens, so that communication is easier when asking for information, when being listened to and attended to. In this way, proximity contributes to promoting equality, in the level of attention of administrations to people and equity in the application of social policies, through recognition of diversity in their needs. Proximity also has the effect of improving efficacy when it facilitates access to resources and services.

Another minimum standard, which should be borne in mind, is the need to overcome negative attitudes and for orientation and support which should be available for people with intellectual disabilities throughout the civil service, in order to provide intellectual accessibility. Therefore, public services should participate in periodic training sessions on intellectual disability to be able to address the specific needs of this group of citizens.

#### **General recommendations**

Public administrations should develop and implement quality plans to assure equality of opportunities to citizens with a disability. For this, they should include in those plans minimum rules of non-discrimination and accessibility, quality indicators and good practice guidance. Some form of certificate of good governance in the field of disability should be adopted in the form of a logo comparable to the logo of physical accessibility.

Access to rights and justice for disabled people requires Member States to fulfil a series of minimum standards and general principles. Furthermore, we should emphasise that public responsibility and good governance are inherent to any action relating to access of disabled persons to rights and justice.

# Good Practice

UNAPEI in France has designed a logo called "S3A" (for "Symbol d'Accueil, d'Accompagnement, d'Accessibilité" = Symbol for Reception, for Support and for Accessibility). This logo denotes that a facility or information source has



for Accessibility). This logo denotes that a facility or information source has been designed for the needs of people with intellectual disabilities. The accommodation it draws attention to can indicate the relevant training of the employees, the availability of easyto-read documents or easily understood information. This logo provides information to the relevant target group and they can expect to receive the service they are looking for with appropriate attention to their special needs.

S3A is a practical response to the concept of "universal access for all" and implements the recommendation R (92) 6 of the Council of Europe "Coherent policy for people with disability" which article 2.3 states: "The symbol of access devised by Rehabilitation International should be used for indicating the location of adapted facilities for people with reduced mobility. Other international symbols, covering other types of disability, should be promoted."

This logo is being tested in the field of public transport, museums and public administrations. It could be a very powerful tool to enhance the accessibility of people with intellectual disabilities to the justice system. It could be used in courthouses' reception desks or in legal assistance organisation offices or in any place where citizens are in touch with the law or justice professionals.

Access to rights requires offering citizens the means to access and places to obtain general information on rights and obligations and personal support in administrative and judicial procedures. In particular, people with intellectual disabilities should receive this support in priority and unconditionally, without having to make any special request or having to prepare an application.

The services available to render effective access to rights and justice should be free of charge. For instance, personal support, information desks, translation into sign language and easy-to-read documents, should be free. Volunteers can be used both for administrative support and for legal information. These can be law students, members of community associations, active and retired members of the public service and retired judges and lawyers. All should undergo a training period of a couple of weeks which would then allow them to offer people with intellectual disabilities legal advice free of charge as a first step in access to justice.

Effective access to justice and rights is a principle of good governance for all administrations. To improve accessibility for intellectually disabled people special attention must be paid to quality orientation, training and awareness raising.

#### 2.3 Improving Access to Public Administrations

People with intellectual disabilities should be able to enjoy the benefits of all public services. To make this possible, public administrations must make their services accessible according to the general principles of mainstreaming, non-discrimination and universal accessibility. They should implement basic standards that are effective and efficient to improve accessibility.

Public administrations are in charge of implementing and monitoring the effective enforcement of legislation in all areas of life. People with intellectual disabilities are not only in contact with social services, but also want to marry, participate in leisure activities, need passports and identity cards, are entitled to housing benefits, etc. Mainstreaming in this context means that all areas of public administration should take care of the needs of people with intellectual disabilities.

The actions developed by public administrations should therefore not be restricted to plans, programmes and specific actions exclusively for people with disabilities, but should satisfy general policies and action lines in all fields of public administration concerned with the needs and demands of people with disabilities. The concerns of people with disabilities need to be included in the programme conception from the outset.

Experiences of people with intellectual disabilities and their families show that the attitudes and behaviours of employees in the public administration are often one of the most important barriers to equal access. Therefore, special attention needs to be paid to awareness-raising seminars for such employees. They should learn about the specific needs and talents of people with intellectual disabilities and about how to communicate with them effectively. It would be of special benefit if those seminars could be organised in cooperation with selfadvocates, i.e. people with intellectual disabilities who speak for themselves.

Furthermore, administrations must adopt and promote clear quality standards for their services, which prohibit any discriminating behaviour of administrative staff. It must be understood that the quality of a public service is closely linked to its ability to serve all citizens, regardless of any disability.

Another important barrier is the accessibility of administrative procedures. Many application forms, official letters or administrative procedures are so difficult to understand that people with intellectual disabilities are excluded from accessing their rights. But not only people with intellectual disabilities suffer from this problem: in some European countries some well-known persons have confessed publicly that they have difficulties in this area.

Therefore, we strongly support all administrative reforms that aim at simplifying administrative procedures and processes. In some areas of special concern for people with intellectual disabilities there should be application forms and guidelines in easy-to-understand language that enable them to access their rights more independently.

In all other areas, personal support is indispensable. Personal support for all citizens with difficulties in reading, writing and understanding must be available at each level of public administration. People with intellectual disabilities should receive this support whenever

necessary, free of charge and without having to make any special request or file an application. It would be preferable if the person responsible for this support would be especially trained, as in the case of a disability Ombudsman who exists in some administrations.

Another important aspect is the coordination of different services. For people with intellectual disabilities it is extremely difficult to deal with different administrations operating under different procedures. A single point of contact would contribute to the simplification of procedures and avoid the duplication of formalities and procedures, as well as possible contradictions.

The above recommendations can be understood as a reasonable accommodation for persons with intellectual disabilities, thus avoiding discrimination in their access to rights. These accommodations must be an integral part of all quality development of administrations and thus be reflected in quality indicators and plans. The partners of the project "Justice, Rights and Inclusion for People with Intellectual Disabilities" welcome and support the initiative to certify good governance in the field of disability in the form of a logo comparable to the logo of physical accessibility.

# **Good Practice**

In France, the proposal for a law on the equalisation of opportunities for persons with disabilities was passed in the beginning of 2005. It creates, at the department level, a single point of contact (unique desk) where people with disabilities can complete all formalities regarding the assessment of their degree of disability, the evaluation of their needs, and where they can apply for a support plan. Furthermore, this unique desk is competent to award some financial allowances and to grant some adjustment measures or reasonable accommodation. This single point of contact is also entitled to provide care counselling towards institutions. Before the implementation of this unique desk, people needed to go to several places and to visit different administrations to complete all the formalities at the departmental level.

#### 2.4 Improving Access to the Legal System

For the purposes of this publication, the "legal system" includes the civil justice system and the criminal justice system. For many countries there are also separate mechanisms and procedures of the justice system to address constitutional issues related to governance. It is also crucial to recognize the importance of the formal and informal institutions that comprise the justice sector. Creating a sustainable environment with equal access to justice requires working with different types of institutions and with various actors, such as the police, the courts, prosecutors, social workers, prison officials, community leaders, paralegals, traditional councils and other local arbitrators, and taking account of the linkages between them.

#### Barriers in access to justice

From the perspective of people with intellectual disabilities, access to the justice system is frequently weakened by:

- Long delays; prohibitive costs of using the system; lack of available and affordable legal representation, that is reliable and has integrity; abuse of authority and powers, resulting in unlawful searches, seizures, detention and imprisonment; and weak enforcement of laws and implementation of orders and decrees;
- Severe limitations in existing remedies provided either by law or in practice. Most legal systems fail to provide remedies that are preventive, timely, non-discriminatory, adequate, just and deterrent;
- Gender bias and other barriers in the law and legal systems: inadequacies in existing laws effectively fail to protect women, children, poor and other disadvantaged people, including those with disabilities and low levels of literacy.
- Lack of *de facto* protection, especially for women, children and men in prisons or centres of detention;
- Lack of adequate information about what is supposed to exist under the law, what prevails in practice, and limited general knowledge of rights;
- Lack of adequate legal aid systems;
- Limited public participation in reform programmes;
- Excessive number of laws;
- Formalistic and expensive legal procedures (in criminal and civil litigation and in administrative board procedures);
- Avoidance of the legal system due to economic reasons, fear, or a sense of futility of purpose.

To ensure equal access to the judicial system, it is important to address these barriers with measures of positive action.

# Good Practice

A free telephone help line should be available 24 hours a day for persons with intellectual disabilities to help them to exercise their rights. This help line should lead to a network of resource personnel in different fields (associations, police, hospitals etc.). It can be a point of first contact and help not only in emergencies, but also in cases where persons with intellectual disabilities have been arrested because of a crime.

#### International standards and instruments

A number of international instruments establish principles and minimum rules for the administration of justice and offer fairly detailed guidance to states on human rights and access to justice. They comprise the European Convention of Human Rights and the Universal Declaration of Human Rights and specific covenants, conventions, rules, guidelines and standards promulgated by the international community under the auspices of the United Nations. Some of them are the following:

The **European Convention of Human Rights** (*http://conventions.coe.int/treaty/en/Treaties/* <u>Word/005.doc</u>) is one of the oldest human rights instruments, which came into effect shortly after the UN General Assembly adopted the Universal Declaration of Human Rights in 1948. It is a very useful tool against discrimination, abuse and neglect of persons with intellectual disabilities.

The <u>International Covenant on Civil and Political Rights</u> (*http://www.unhchr.ch/ html/menu3/b/a\_ccpr.htm*) enshrines the principles of equality before the law and the presumption of innocence, and includes guarantees of freedom from arbitrary arrest and detention and the right to a fair and public hearing by a competent, independent and impartial tribunal established by law.

The independence of the judiciary is addressed in the <u>Basic Principles on the</u> <u>Independence of the Judiciary</u> (*http://www.unhchr.ch/html/menu3/b/h\_comp50.htm*). This instrument requires that the independence of the judiciary be guaranteed by national law and prohibits the inappropriate and unwarranted interference with the judicial process. Furthermore, it protects due process through established legal procedures that are fair and respects the rights of the parties. It also obliges states to provide adequate resources to enable the judiciary to properly perform its functions, and sets forth principles for the selection, training and conditions of service and discipline of the judiciary.

The **Basic Principles on the Role of Lawyers** (*http://www.unhchr.ch/html/menu3/b/* <u>h comp44.htm</u>) requires governments to ensure that efficient procedures and responsive mechanisms for equal access to lawyers are provided, including the provision of sufficient funding and other resources for legal services to the poor and other disadvantaged persons. In addition, it entitles lawyers to form and join self-governing professional associations, while at the same time such professional associations are required to cooperate with governments in the provision of legal services.

The <u>**Guidelines**</u> on the <u>Role</u> of <u>Prosecutors</u> (*http://www.unhchr.ch/html/menu3/b/ h\_comp45.htm*) identify the responsibility of prosecutors in protecting human dignity and upholding human rights and ensuring due process. The *Guidelines* also strictly separate judicial functions from the office of the prosecutor.

Requirements of law enforcement officials, including military authorities that exercise police powers, are set out in the <u>Code of Conduct for Law Enforcement Officials</u> (*http://www.unhchr.ch/html/menu3/b/h\_comp42.htm*). The *Code*, among other things, requires officers of the law to uphold the human rights of all persons and to provide particular assistance to those who, by reason of personal, economic, social or other emergencies are in need of immediate aid.

Several international instruments address the rights of prisoners and detainees. Among them, the **Basic Principles for the Treatment of Prisoners** (*http://www.unhchr.ch/html/menu3/b/h\_comp35.htm*) prohibits discrimination, insists on respect for human rights as contained in international instruments and calls for the reintegration of ex-prisoners into society under the best possible conditions and with due regard to the interests of victims.

#### Measures to improve access to rights and justice

The *United Nations Development Programme* provides a useful overview of different measures that can improve access to justice:

Legal protection	Provision of legal standing in formal or traditional law involves the development of capacities to ensure that the rights of disadvantaged people are recognized within the scope of justice systems, thus giving entitlement to remedies through either formal or traditional mechanisms. Legal protection determines the legal basis for all other support areas on access to justice. Legal protection of disadvantaged groups can be enhanced through: (a) Ratification of treaties and their implementation in domestic law; (b) implementation of constitutional law; (c) national legislation; (d) implementation of rules and regulations and administrative orders; and (e) traditional and customary law.	-	Parliament Ministries of Foreign Affairs International/regional fora Ministries of Law and Justice, police forces National Human Rights Commissions Law Reform/Legislative Commissions Legal drafting cells of relevant ministries Local officials involved in legal drafting Judges, particularly of courts whose decisions are binding on lower courts or are able to influence courts in other jurisdictions Traditional Councils Community leaders (chiefs, religious leaders)
Legal awareness	Development of capacities and effective dissemination of information that would help disadvantaged people understand the following: (a) their right to seek redress through the justice system; (b) the various officials and institutions entrusted to protect their access to justice; and (c) the steps involved in starting legal procedures.		Ministry of Justice Ministry of Education/higher education, schools and universities National Human Rights Institutions Legal aid providers Quasi-judicial bodies (human rights, anti- corruption, and electoral commissions). Local government bodies Non-governmental institutions (e.g. NGOs, Bar associations, universities, communities) Labour unions
Legal aid and counsel	Development of the capacities (from technical expertise to representation) that people need to enable them to initiate and pursue justice procedures. Legal aid and counsel can involve professional lawyers (as in the case of public defence systems and <i>pro bono</i> representation), laypersons with legal knowledge (paralegals), or both.	- - - - -	Ministries of Justice and state-funded legal aid programmes Public Attorneys Court system (e.g. to deal with court fees) Local governments Police and the prison system Non-governmental organizations (NGOs) Bar associations Law clinics (often linked to university faculties of law)
Adjudication	Development of capacities to determine the most adequate type of redress or compensation. Means of adjudication can be regulated by formal law, as in the case of courts and other quasi- judicial and administrative bodies, or by traditional legal systems.	-	Courts National human rights institutions (Human Rights Commissions and Ombudsman Offices) Alternative dispute resolution mechanisms: these can be attached to the court system, or be administrative bodies (such as land and labour boards)

Enforcement	Development of capacities for enforcing orders, decisions and settlements.	- -	Prosecution Formal institutions (police and prisons) Administrative enforcement
Civil society and parliamentary oversight	Development of civil society's watchdog and monitoring capacities, so that it can strengthen overall accountability within the justice system.	-	NGOs working on monitoring and advocacy Media Parliamentary select and permanent committees

In the case of disabled persons, access to rights has certain features in the area of justice, which make specific intervention necessary. It should be taken into account that persons with intellectual disabilities may not be able to follow complex information or to resolve conflicts. Because of this, it is extremely important to take positive action measures into account to avoid discrimination in access to justice, particularly in the case of penal prosecution where these persons may be either the subject or victim of an offence.

#### Legal awareness

Legal awareness is the foundation for fighting injustice. People with intellectual disabilities cannot seek remedies for injustice if they do not know what their rights and entitlements are under the law. Information on remedies for injustice must be intelligible to the public. Knowledge provided to them, in simple language and pictures, must serve their practical needs.

Strategies to promote legal awareness should be undertaken by both government and nongovernment actors. There are governments who do not meet their obligation to inform the public about relevant rights and entitlements and those who lack the capacity to comply with such an obligation. Both of these common deficiencies need to be remedied. On the other hand, although there are many human rights organisations engaged in legal awareness activities targeted at disadvantaged groups, their impact is often limited by uncoordinated efforts, dispersion, and unsustainable programmes. The following points could be of practical use:

- Support communication policies and mechanisms for dissemination of legal information. Communication strategies should be adequate to the needs and aspirations of persons with intellectual disabilities. Therefore, they should include employment of paralegals, production of information in user-friendly formats, as well as pro-active dissemination of knowledge to those who face substantial physical, intellectual, or economic barriers.
- Adopt a demand-driven orientation and focus on the needs of disadvantaged groups in response to specific problems. Knowledge of specific laws and regulations (for example anti-discrimination legislation) can be of more practical value compared to general knowledge of international norms or constitutional principles. Among the popular education modalities that may be worth supporting are: public radio or television shows, street theatre, information kits/flyers on how to initiate legal action for those who cannot afford to hire a lawyer, legal information kiosks or centres, and Website resource pages.

# Good Practice

In Spain, CERMI (the Commission of Representatives of Disabled Persons), ONCE (the National Organisation of the Blind) and the Council of Law carry out joint actions for the promotion of access to justice for people with disabilities.

- They have promoted the "Citizen's Bill of Rights" before the justice administration.
- They have promoted accessibility and the elimination of barriers in the head office of the General Council of Spanish Law (CGAE).
- In the "Service of Free Justice", they have promoted an advisory and orientation service for people with disabilities.
- These three institutions collaborate with University Faculties of Law about the needs of lawyers with disabilities.
- They have achieved the adhesion of the General Council of Spanish Law (CGAE) to the Madrid Declaration about people with disabilities and its compromise for the fulfilment of the legal quota relating to employment of people with disabilities or alternative measures.
  - Involve non-lawyers in design and delivery of community education programmes. Experience indicates that social professionals, community organizers, teachers, religious leaders and others with non-legal skills can make substantial contributions to public awareness of the law, their rights and other legal remedies they are entitled to.

#### Legal aid

Legal awareness can help people with disabilities understand that they have rights, such as protection from discrimination in employment and occupation. Remedies for violations of such rights often require the intervention of lawyers. Costs associated with the services of legal counsel and legal processes tend to discourage those who cannot afford them from seeking just remedies. Legal aid support can counter some of these impediments.

Government legal aid schemes include forms of financial and social support, such as exemptions in procedural costs and social services to victims and witnesses. Governments can also be actively involved if they have the capacity to provide legal aid to the poor, by implementing legal aid or mediation services (e.g. deployment of public defenders and other legal counsels for free).

Non-government legal aid systems can provide supplemental services with pro-bono attorneys, legal clinics and alternative law and public interest law groups. Non-government services are not a substitute for state responsibility to provide legal aid, although they are a key source of assistance to the poor and the disadvantaged, especially where local governments lack the capacity to fulfil their responsibilities.

Non-government activities can also improve the overall quality of professional education, while expanding services for the poor. Strategies may include institutionalisation of

community services for law graduates and retired professionals and establishment of university law clinics.

Legal aid schemes can benefit from the use of volunteers and paralegals, and utilise existing structures at the local level to expand access and quality of service. Poor people frequently require advice and assistance that avoid the need for cases to be tried, including alternative dispute resolution mechanisms and other informal settlements. They may also require advice on whether they need legal representation, and where they could find *pro bono* lawyers. Paralegals or volunteers with specialized training in providing legal assistance to disadvantaged groups can give such advice.

#### Adjudication / Mediation

Adjudication and mediation involve the process of determining the most appropriate type of remedy or compensation. Adjudication mechanisms include judicial and quasi-judicial processes.

For people with intellectual disabilities, these processes are one of the most important mechanisms for access to rights and justice. Adjudication and mediation procedures do not require a lengthy and complex legal process and are generally less costly. Their more informal nature makes them more accessible for people with intellectual disabilities.

There is a general tendency for justice sector reform to focus overwhelmingly on programmes supporting formal mechanisms of justice and especially processes of adjudication through the judiciary. This is understandable from a government perspective. However, in terms of access to justice it is essential that common parameters of assessment be applied to both formal and informal legal mechanisms.

Quasi- and non-judicial choices include National Human Rights Institutions (NHRIs) and alternative dispute resolution mechanisms. There are basically two types of NHRI: Human Rights and anti-discrimination commissions, and the Ombudsman offices. NHRIs are generally non-governmental organisations that can help poor and disadvantaged people reach remedies that would otherwise remain inaccessible to them. The presence of NHRIs may also be useful to prevent future problems since they generally have a monitoring role, as well as one that promotes long-term, sustainable mechanisms, such as public education on human rights.

#### **Good Practice**

Mediation for people with intellectual disabilities should exist as a prerequisite in all judicial proceedings of civil law. Only when this does not lead to results should a court hearing take place. The participation of bodies with a legitimate interest (disability or other representative organisations) in every kind of judicial proceedings, together with disabled persons and their families, should be actively promoted.

#### **Personal support**

According to a special provision on access to justice in the draft of the UN Convention for people with disabilities, each State should take appropriate and effective measures to ensure accessibility to judicial proceedings of persons with intellectual disabilities. They should also try to eliminate all physical, social, informational, communicational, linguistic or other barriers to facilitate the effective exercise of the rights and participation in all official proceedings of a person with intellectual disabilities.

To guarantee equal opportunities for all disabled persons, complementary support should be established (personal services), such as the presence of a support person who could facilitate the communication, information and orientation of the person with an intellectual disability in all processes relating to access to justice.

#### 2.5 People with Intellectual Disabilities in the Criminal Justice System

The project "Justice, Rights and Inclusion for People with Intellectual Disabilities" has highlighted the special problems that people with intellectual disabilities face when in contact with the criminal justice system. Their limited literacy and intellectual skills lead, in many European countries, to the fact that a larger number of people with intellectual disabilities are in normal prisons.

#### The procedure before the court hearing

In cases where a person with intellectual disabilities is involved in a trial and is accused of a crime, police officers and court officials often fail to identify an individual as having an intellectual disability. Therefore, apart from sensitising and training the staff throughout the civil service about intellectual disability, intervention protocols including a psychological assessment of those under trial might be appropriate. If there is a justified doubt about a defendant's competency at any time throughout the judicial proceedings, an evaluation by a psychologist with expertise in intellectual disability is suggested. Where a person with intellectual disability is the victim of a crime, it is most important that any proceedings that follow (interrogations, first hearing, face to face confrontation with the aggressor, etc.) take into account his/her particular needs. Where appropriate, lawyers should ensure that judges and jury are aware that non-verbal behaviour such as staring, sleeping and smiling, exhibited by a defendant with intellectual disability, does not necessarily demonstrate lack of respect.

Justice reform processes too often fail to include **police reform**. However, the police play a fundamental role in ensuring access to justice, particularly since it is the point of first contact in the criminal justice system. Police performance may be affected by poor investigation and forensic capacities, weak oversight, corruption and a widespread culture of violence. Strategies to enhance police performance include strengthening investigative capacities, institutional structures of control, training standards, and improving community-police relations. The training of the police staff in identifying cases of discrimination and understanding the needs and capacities of people with intellectual disabilities will contribute to avoiding situations of discrimination.

Defendants with intellectual disabilities are often inadequately represented because court officials do not understand this disability, or because appropriate steps have not been taken to understand the capabilities and limitations of an individual with intellectual disabilities. Defendants with intellectual disabilities are often tried without sufficient assessment of their competence to stand trial.

The courts should take affirmative measures to avoid discrimination and enable effective participation in court proceedings. In particular, court personnel should make reasonable provision in policies, practices and procedures, whenever necessary, in order to avoid discrimination based on disability, which would not fundamentally alter the nature of the proceeding. One measure that could be recommended is that of establishing co-ordination with specialised entities in the world of intellectual disability, which could serve as support and guidance for the disabled person, his family and for legal personnel as well.

When experts are necessary, it is recommended to use individuals with professional education and experience in the field of intellectual disability, as well as experience in court. Judges should consider appointing a lawyer to represent a person with intellectual disability, who is experienced in defending and handling cases of persons with disabilities.

#### The procedure during the court hearing

In the courtroom a person with an intellectual disability, whether the perpetrator or victim of a crime, may:

- not be competent to stand trial, as he/she may have difficulty understanding judicial proceedings, be unable to understand the charges, or be unable to assist his/her lawyer;
- not be competent to confess, as he may be extremely vulnerable to pressure during interrogation, unable to give an accurate and reliable confession, sometimes eager to please the judges by confessing;
- not be competent to plead guilty, as he/she may be unable to understand legal terms, be unable to understand the consequences of his/her actions, be confused about who is responsible and plead guilty without understanding why, even though innocent.

If the possibilities set out above are not taken into account, we may well be faced with a situation of discrimination. In order to avoid unfair judgements, the court personnel should consider the following measures:

- Use simple wording that does not include complex terms;
- Take time giving or asking for information and repeat questions more than once, if necessary, when conducting interviews or trials;
- Always use non-leading questions when questioning a person with intellectual disability and ask in a straightforward, non-aggressive manner;
- Consider reserving additional time for people with intellectual disabilities to understand trial communications. For example, the lawyer of an intellectually disabled person may need additional time to explain carefully what the judge is saying;
- The lawyer of a person with intellectual disability should use a support person (a relative, friend or professional who can better understand the person's communication skills) to ensure that the client understands the trial activities;

- When testifying, the person with the intellectual disability should be allowed to have access to emotional support via counsellors, family members or supporters, and should be physically close to them in order to reduce any anxiety;
- Adopt measures necessary to assist an intellectually disabled victim of a crime to make a declaration without having to confront the aggressor, e.g. by using the videoconference method, or being able to declare in the absence of the aggressor;
- When pronouncing their decision, judges should always choose the least restrictive environment for a person with intellectual disability. For example, a community-based treatment programme for offenders with intellectual disabilities may be more appropriate than an institution or imprisonment. Courts should consider using alternatives to sentencing, such as probation and other diverting community-based programmes, when deciding the case. Alternatives to sentencing may include community service hours, or housing with guardianship, special education centres, etc.

#### The procedure after the court hearing

Once the judicial proceedings are over and the ruling is pronounced, in the case of people who have committed a crime, it is important to bear in mind that their intellectual disability should be considered during penitential treatment (if the decision includes imprisonment).

In such cases, it is recommended that organisations specialising in disability incorporate intervention programmes in their work for intellectually disabled persons who are imprisoned. Such measures would require intensive co-ordination with members of the prison staff.

Prisons usually are being left out of most justice reform processes. Yet, the prison system tends to suffer from the consequences of problems that originated in other parts of the justice system, as is the case with judicial delays or unnecessary imprisonment. However, prison systems are a low priority for most governments. Consequently, prisoners continue to be housed in poor living conditions. Strategies to improve the penal system may include improving conditions of detention, strengthening informal justice at the local level, enhancing technical and human rights training for prison managers, enhancing transparency of the prison system as a means of protecting prisoners, and socially constructive measures which encourage the social re-integration of offenders.

In case the judgement of the Court has not taken into account the intellectual disability of the condemned person, or this was not detected during the proceedings, judicial mechanisms should be used which would allow the reconsideration of the punishment. In many cases, a situation of social exclusion and extreme poverty leads to intellectual disability not having been appropriately diagnosed, which means that many people can find themselves serving a sentence without their situation being attended to, and this implies obvious discrimination which ought to be avoided.

#### Case study: People with intellectual disabilities in the penitentiary system in Spain

The project partner FEAPS, the Confederación Española de Organizaciones en favor de las Personas con Discapacidad Intelectual, has developed a comprehensive Social Integration and Rehabilitative Activities Programme for Prisoners and ex-Prisoners with intellectual disabilities. This programme was initiated in 1995. It resulted from a visit to the prison in León.

During this visit the inappropriate treatment received by imprisoned persons with intellectual disabilities was noticed. The need for a programme was confirmed to promote the rehabilitation of these prisoners, with the aim of achieving their re-integration into society after serving a prison sentence or punishment.

Three key areas can be distinguished in the Programme:

- Study and research actions: Oriented towards understanding the reality and needs of persons with intellectual disabilities in prisons;
- 2. Activities:

Aimed at improving the situation of persons with intellectual disabilities who are serving a prison sentence, the activities for the prevention and obtaining of more rehabilitative sentences, as well as improving the follow-up of ex prisoners;

 Network of centres and services: Aimed at serving the sentence or preventive measure for persons with intellectual disabilities either in prison or in a more rehabilitative environment.

The Programme is geared to people with intellectual disabilities who are officially recognised by the corresponding Handicap Certificate and happen to be in any one of the following situations:

- People in a situation of criminal risk who have committed anti-social acts and/or inhabit family or group environments where there is delinquency or pre-delinquency;
- Persons affected by the penitentiary penal regime who have committed an offence or crime and who are in any one of the following situations: awaiting trial, preventive detention, on probation with security measures, imprisoned and on probation;
- Ex-prisoners who have been released.

It should be noted that intellectual disability in itself does not necessarily determine criminal behaviour. However, as with the population in general, there are influencing factors such as poverty, social isolation, exclusion, family, unstructured surroundings and lack of affection, all of which, together with the vulnerability of persons with intellectual disabilities, can increase the possibility of offences being committed.

It is important to reflect that this group shares the typical profile of most general features of prisoners; added to this is intellectual disability, which implies even greater defencelessness when faced with the demands of daily life and survival in extremely problematical surroundings.

The activities carried out in the Programme are differentiated, depending on whether intervention is made inside or outside prisons.

# Activities inside prisons

• **Detecting new cases**: The technical staff in prisons may be in a position to indicate prisoners who may possibly have intellectual disabilities. The programme team then carries out evaluations using clinical interviews, psychological tests, and consulting clinical

backgrounds. Where the diagnosis of intellectual disability is confirmed, a programme for individual intervention will be designed.

- Making the diagnosis official: Obtaining a Handicap Certificate.
- **Individual plans for rehabilitation and treatment**: These embrace the areas of personal life, family, social relations and work. These plans need an adaptation to the prison environment in two aspects:
  - a) Adaptation to the prison environment: achieving appropriate placement and interaction within the prison;
  - b) Preparation for release and re-integration: rehabilitation (health, training, work preparation, psychological attention) and re-integration (family, social) in co-ordination with resources and social services.
- **Occupational programmes and social or work re-integration**: Incorporating the programmes into workshops, classrooms, etc., as well as into activities in prisons considered to be appropriate. Education programmes.
- Follow-up and channelling of the needs and demands of the prisoner.
- Leisure time activities and therapeutic outings: Promote new, healthy, enriching alternatives to the use of toxic substances. The idea is to create a relation with a normal social environment, strengthen habits of personal autonomy, encourage and consolidate the social abilities practised in the corresponding individual programme and, in certain cases, to facilitate relations with their families.

#### Activities outside prisons

- **Detecting needs, demands and new cases**: Individual assessment and the development of a personalised work plan.
- **Social and work re-integration programmes**: Inclusion in programmes of training and occupational work integration with support, in ordinary enterprises and in other services.
- Follow-up and evaluation of users.
- **Transfer of ex-prisoners or those on probation**: Once on probation, a judicial ruling will pass judgement on serving a sentence in an alternative centre, or the ex-prisoner will receive clinical treatment. The technical prison staff will transfer the person to an occupational centre, a leisure centre, residential resources, etc., depending on the situation.
- Search for and promotion of alternatives to prison through a network of alternative resources.
- **Social assessment**: Social work intervention with the families and environments of these people.

- **Handling and transaction of documentation**: The handling of documentation such as the national identity card, preparing multidisciplinary reports for obtaining official Handicap Certificates, certificates of local census registration, handling of pensions, etc.
- Legal assessment, revision of cases: The main objective is to offer legal support to the group being addressed. Actions will be carried out in the prison ambit (the study and evaluation of Programme users, including penal, proceedings and prison information; revision of sentences, assessment and information, writing of reports, etc), in the legal ambit (preparing court declarations/citations, initiating procedures for disability), and in other fields (for example, attention and assessment for families).
- **Preventive activities**: Prior measures to achieve more rehabilitative and sensitive sentences and punishments. Continuity in the Programme for ex-prisoners to avoid relapse.
- **Sensitisation and circulation activities**: elaboration of leaflets, Awareness Day for Associations, periodical publication of articles, contacts with professional associations of judges, lawyers and public prosecutors, dissemination of the programme in the media, organisation of and participation in Seminars, Congresses, Technical Conferences, etc.
- **Training activities**: Organisation of courses and training seminars for people registered on the programme and/or professionals involved with the group.

#### 2.6 Conclusions

Detailed discussions with member societies of Inclusion Europe, as well as additional research carried out in the framework of this project have demonstrated that people with intellectual disabilities have difficulties in access to rights and justice in all EU Member States and accession countries, as well as in other Council of Europe member states. Equal access to rights and justice is fundamental in order to reduce poverty and social exclusion and to strengthen democratic governance.

Due to this limited access to their rights, people with intellectual disabilities often lack the possibilities to fight actively against their social exclusion. Justice and administrative reforms with the objective to accommodate those who are disadvantaged would therefore lead to the empowerment of people to stand up for their own rights. After centuries of social exclusion, people with intellectual disabilities are increasingly committed to claim their rights and to use the justice system, if necessary. Governments and the European Union have the obligation to support this process by making sure that all their citizens, without exception, have access to rights and justice.

It has been demonstrated in this publication how the fundamental principles of selfdetermination, universal access and equal citizenship can guide these efforts towards access to rights and justice for people with intellectual disabilities. Most important in these efforts is the development of a comprehensive and coordinated strategy, in combination with clear standards and indicators, which aims to reach all levels of public administration and justice. It must be the objective of all levels of government to ensure and enforce non-discrimination for all their citizens.

For people with intellectual disabilities, the most important requirement concerns legal awareness in terms of access to information on rights and obligations, as well as personal support in administrative and judicial procedures. They need this support unconditionally and without having to make any special request. People with intellectual disabilities also need access to adjudication and mediation procedures that can be moderated much better in a way to accommodate the special needs of this group of citizens.

The most difficult consequence of a limited access to justice has to be seen in the fact that in most European countries a significant number of people with intellectual disabilities seem to serve a sentence in normal prisons. This is an indication of the fact that their rights and intellectual limitations were not properly taken into account by the justice system and is one of the most important arguments for better accessibility and necessary support.

For European citizens with intellectual disabilities the principles for access to rights and justice enshrined in the European Convention of Human Rights and in the Universal Declaration of Human Rights must become a reality.

### Annex

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#### **Relevant websites**

- <u>http://www.coe.int/</u> The website of the Council of Europe
- <u>http://www.echr.coe.int</u>
   The website of the European Court of Human Rights
- <u>http://bailii.org</u>
   The website of the British and Irish Legal Information Institute
- <u>http://www.curia.eu.int</u> The website of the European Court of Justice
- <u>http://www.interights.org</u> The website of the International Centre for the legal protection of Human Rights
- <u>http://drc-gb.org</u>
   The website of the Disability Rights Commission
- <u>http://www.lawreform.ir</u>
   The website of the Law Reform Commission of Ireland
- <u>http://www.un.org/esa/socdev/enable/index.html</u> The website of the United Nations about disability
- <u>http://www.vgt-ev.de</u>
   Website of a national non-profit organization for the discussion and development of "Betreuungsrecht"
- <u>http://www.betreuung-mit-zukunft.de</u>
   Website with lots of material about Betreuungsrecht
- <u>http://www.betreuerlexikon.de</u>
   Website of an online-encyclopaedia about Betreuungsrecht
- <u>http://www.bmj.bund.de</u>
   Website of the German Federal Ministry of Justice with links to all German laws;
- <u>http://www.dzieci.org.pl/index.php</u>
   Polish website about children with disabilities
- <u>http://www.bardziejkochani.pl/</u>
  Polish website of the Association of Parents of Children with Down syndrome
- <u>http://www.rpd.es</u>
   Spanish website of the Royal Board on Disability Ministry of Labour and Social Affaires (Real Patronato sobre Discapacidad)
- <u>http://imsersodiscapacidad.usal.es</u>
   Spanish website of the Observatorio de la Discapacidad (ODC) IMSERSO
- <u>http://www.siis.net</u>
   Spanish website of the Documentation and Studies Centre of the Eguía-Careaga
   Foundation (SIIS.Centro de Documentación y Estudios)
- <u>http://www.cermi.es</u>
   The website of the Spanish National Council of Disabled Representatives (Comité Español de Representantes de Personas con Discapacidad)
- <u>http://www.discapnet.es</u> The website of the Fundación ONCE - Fondo Europeo de Desarrollo Regional
- <u>http://www.rechtspraak.nl</u>
   Website about the judiciary system in the Netherlands

# Contact details of the participating Organisations

#### Belgium

 Inclusion Europe Geert Freyhoff Galeries de la Toison d'Or 29 Chaussée d'Ixelles #392/32 B-1050 Brussels Website: <u>www.inclusion-europe.org</u>

#### Germany

- Bundesvereinigung Lebenshilfe f
  ür Menschen mit geistiger Behinderung Ulrich Hellmann Raiffeisenstr. 18 D-35043 Marburg Website: <u>www.lebenshilfe.de</u>
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#### France

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- Biuro Rzecznika praw Obywatelskich (Office of the Commissioner for Civil Rights Protection) Michal Kubalski Aleja Solidarnosci 77 PL-00-090 Warszawa Website: <u>www.brpo.gov.pl</u>

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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 34 countries.

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, Czech, Dutch, Polish and Spanish. 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
- Polskie Stowarzyszenie na Rzecz Os-b z Upoćledzeniem Umys,owym, Poland
- Biuro Rzecznika Praw Obywatelskich, Poland
- Confederación Española de Organizaciones en favor de las Personas con Discapacidad Intelectual (FEAPS), Spain
- Sdruěen' pro pomoc ment‡lnž postiěenům, Czech Republic
- Lehrstuhl für Bürgerliches Recht, Zivilprozessrecht und Rechtsvergleichung, Universität Göttingen, Germany
- Depto. Trabajo Social y Servicios Sociales, Universidad de Alicante, Spain
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