FORGOTTEN EUROPEANS – FORGOTTEN RIGHTS

THE HUMAN RIGHTS OF PERSONS PLACED IN INSTITUTIONS
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I. Introduction

A. SCOPE AND PURPOSE OF THE REPORT

This report has been prepared on behalf of the Regional Office for Europe of the United Nations Office of the High Commissioner for Human Rights (OHCHR). It highlights one of the most significant human rights challenges in Europe today, namely that many children, persons with disabilities and older persons continue to be placed in long-stay residential institutional care in countries across Europe, often for life.

This report is the first of a series of OHCHR publications intended to inform and encourage debate on the issues affecting children, persons with disabilities and older persons in institutions and how the areas of concern should be addressed. Its overriding purpose is to draw attention to two issues: first, the situation of children, persons with disabilities and older persons living in institutions and second, the responsibility of Governments to develop community-based alternatives to institutional care. Both are of crucial importance. While Governments need to develop and implement strategies for the shift from institutional care to community-based services, they must also protect the rights of individuals who remain in institutional care during this transition process.

Accordingly, this report identifies and compares a range of United Nations and Council of Europe human rights standards that are of particular relevance to children, persons with disabilities and older people who are currently, or are at risk of being, institutionalized. Given the broad scope of the study, this report does not purport to cover each and every human rights standard that may be of relevance. Nor does it claim to provide a definitive interpretative guide on how different standards impact upon each other. Rather, the report seeks to identify the main issues currently covered by the relevant standards and to highlight any areas that merit further consideration and discussion.

1. The definition of “institutional care”

This report uses the term institutional care to mean the provision of care in “traditional” long-stay institutions, i.e., premises in which residents have little, if any, control over their lives and day-to-day decisions. While such premises often house large numbers of people, the size of the building is only one of a number of factors that create a culture of institutionalization. Others include rigidity of routine, such as fixed timetables for waking, eating and activity, irrespective of individuals’ personal preferences or needs.

The term formal care settings is used to denote both traditional long-stay institutions and the residential care settings which form a part of the range of community-based services that Governments are encouraged to develop.

2. The importance of developing clear standards for the provision of care and support

Clear standards for the provision of services to all children, older people and persons with disabilities who are in need of care and support in settings other than their home environment will be required. This is crucial given the slow progress in developing community-based alternatives to institutional care. Even where concerted action is taken, the transition from a system of institutional care to community-based services can take time. Robust safeguards must therefore be established to help protect the rights of those individuals who remain in institutional care.

In addition, the range of community-based services needed as alternatives to institutional care is likely to include some form of residential care for individuals who may wish to receive (whether on a temporary or on a longer-term basis) care and support in settings other than their home environment. Clear standards for the provision of care and support in these settings will be essential to ensure that residents are treated with dignity and respect for their human rights.
B. THE PREVALENCE OF INSTITUTIONALIZATION

It is estimated that nearly 1.2 million children and adults with disabilities are living in long-stay residential institutions across the European Union (EU) member States and Turkey. Another survey estimates that there are 150,000 children living in residential care settings across the EU (these include special schools, infant homes and homes for people with disabilities).

Both in Europe and internationally, placement in institutional care and the conditions in such facilities are recognized as acts giving rise to major human rights challenges.

The situation of people in long-stay residential institutions in Central and Eastern Europe is of particular concern. Numerous reports have noted substandard living conditions, including badly maintained buildings, lack of heating and unhygienic sanitation; poor treatment of residents, including inadequate provision of clothing and food, sometimes leading to malnutrition, physical and sexual abuse, lack of privacy and few or no rehabilitative or therapeutic activities; as well a failure to respect procedural safeguards such as review of involuntary placements.

Institutionalization itself can lead to serious and often long-term adverse consequences for persons of all age groups, but it is particularly harmful for children. The lack of emotional attachment is very damaging to their development. The World Report on Violence Against Children noted that the impact of institutionalization on children is severe. It can “include poor physical health, severe developmental delays, disability, and potentially irreversible psychological damage”.

Yet Central and Eastern Europe (together with the Commonwealth of Independent States) has the largest proportion of children in institutions in the world, and the rate of placement in formal care in these regions is increasing. Many of these children are not orphans (although the institutions where they are placed are commonly known as “orphanages”). This is because it is poverty, rather than lack of family, that leads to many placements.

Research indicates that children under the age of 3 continue to be placed in institutions despite the growing consensus that this is extremely damaging to their health, well-being and development.

The Committee on the Rights of the Child has also raised concerns about the “considerable overrepresentation of Roma children among children in institutions” in some parts of Central and Eastern Europe.

Against this background, as will be seen in the following chapters, both the United Nations and the Council of Europe have stressed the need for Governments to take action to address the institutionalization of adults and children. For example, the Council of Europe Committee on the Rehabilitation and Integration of People with Disabilities considers that “institutional care is incompatible with the exercise of children’s rights and should be phased out”. This reflects not only the concerns about the serious human rights violations that occur within institutions, but also that placement in institutions itself excludes individuals from society and prevents them from exercising their rights as equal citizens, in particular the right to live and participate in the community (discussed further below).

C. ANALYSIS OF RELEVANT HUMAN RIGHTS STANDARDS

This report considers a range of human rights standards, both those that are of general application as well as those specific to children, persons with disabilities and older persons, including the standards specific to individuals placed in mental health facilities. They are set out in the annex to this report and include the following categories of human rights instruments:

- United Nations and Council of Europe legally binding treaties
- Relevant cases and decisions of United Nations and Council of Europe bodies
- General comments/recommendations arising from the United Nations treaty bodies
- Guidelines, recommendations, other instruments and reports issued by the United Nations and Council of Europe
Status of United Nations and European human rights instruments

There are nine core human rights treaties within the United Nations human rights framework, each of which has established a committee of experts to monitor the implementation of the treaty provisions by their States parties, i.e., the States that have ratified them. Some of these treaties are supplemented by optional protocols dealing with specific concerns or providing for an individual complaint mechanism. These treaties and optional protocols are legally binding on the States parties. In addition to the human rights treaties, there are a wide range of universal human rights instruments which, although not legally binding, have an undeniable moral force and provide practical guidance to States in their conduct.

A similar situation exists at the European level. The 27 members of the EU have undertaken to respect and promote the human rights of their citizens. So have the 47 members of the Council of Europe. Within the Council of Europe there is a range of human rights treaties, such as the Convention for the Protection of Human Rights and Fundamental Freedoms, known as the European Convention on Human Rights (ECHR) and the European Social Charter, with protocols that add to, or revise, the relevant treaty. These are legally binding on the States that have ratified them. In addition, there is a range of recommendations and guidelines that are not legally binding but are intended to provide guidance to States on how they should adapt laws and policies in order to comply with their obligations under the relevant treaties. The jurisprudence arising from the European Court of Human Rights has great influence as the Court decides on the extent of States’ obligations under the ECHR.

Convention on the Rights of Persons with Disabilities

The most recent of the United Nations core human rights treaties is the United Nations Convention on the Rights of Persons with Disabilities (CRPD). This came into force on 3 May 2008 and to date, 100 States have ratified it. The European Union ratified the CRPD on 23 December 2010. The CRPD is the first international human rights treaty to be ratified by the EU.

The introduction of the CRPD is of huge significance for the human rights of persons who are institutionalized. This is because the CRPD marks a paradigm shift in attitudes and approaches to persons with disabilities, requiring that they no longer be regarded as “objects” of charity, medical treatment and social protection. Rather, persons with disabilities have the same rights as others to enjoy all human rights and fundamental freedoms and are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.

Children and older persons who are “persons with disabilities” as described in the CRPD will be covered by that Convention as well as by general comments and guidance emanating from the Committee on the Rights of Persons with Disabilities (hereafter “CRPD Committee”).

While not all children and older persons living in institutions will have disabilities, the new approach to persons with disabilities contained in the CRPD is likely to have an impact on members of other groups who are placed in institutions. For example, article 19 of the CRPD provides that persons with disabilities have the right to live and participate in the community “with choices equal to others”. States parties are required to “take effective and appropriate measures” to facilitate the “full inclusion and participation in the community” of persons with disabilities. Although the CRPD is specific to persons with disabilities, article 19 is founded on rights that apply to everyone. It emphasizes the importance of developing good-quality and sustainable alternatives to institutional care. This requires “the shift of government policies away from institutions towards in-home, residential and other community support services”. The right to live and participate in the community is discussed in more detail in chapter VII.

Human rights instruments specific to formal care

In addition to considering the core human rights treaties mentioned above, this study considers specific human rights standards that focus on the situation of children, persons with disabilities and older people who are placed in formal care, or are at risk of being so placed.

Of the non-binding instruments, the Guidelines for the Alternative Care of Children are of key significance in relation to children. A core principle of these guidelines is that “efforts should primarily be directed to enabling the child to remain in or return to the care of his/her parents, or when appropriate, other close
family members” (para. 3). They emphasize that the removal of children from their families “should be seen as a measure of last resort and should, whenever possible, be temporary and for the shortest possible duration” (para. 14) and that alternative care for young children, especially those under 3 years, should be provided in family-based settings (para. 22).

Both the United Nations Principles for the protection of persons with mental illness and the improvement of mental health care of 1991 (hereafter “the MI Principles”) and Recommendation Rec(2004)10 of the Committee of Ministers of the Council of Europe concerning the protection of the human rights and dignity of persons with mental disorder focus on the provision of mental health care. (In some cases, these provisions will cover persons with intellectual disabilities as well as those with mental health problems, also referred to as “psycho-social disabilities”). In the past, these human rights instruments have been of significant influence and therefore they have been included in this study. However, as highlighted in subsequent chapters of this report, both will need extensive revision in the light of the rights set out in the CRPD. To the extent that these standards conflict with the CRPD, the relevant provisions will be obsolete. It will be for the CRPD Committee to provide an authoritative interpretation thereon, but in the meantime this report identifies some issues that require close attention.

Thus far, no guidance specifically addressing the care and treatment of older persons in formal care settings has been developed. However, the standards that focus on the specific rights of older persons, such as CESCR general comment No. 6 (1995) on the economic, social and cultural rights of older persons, the United Nations Principles for Older Persons and the Political Declaration and Madrid International Plan of Action on Ageing, 2002 will be referred to where relevant.

Standards concerning persons who are deprived of their liberty and the administration of justice will also be considered. This is because in some cases, people may be placed in formal care settings as a result of an order of any judicial, administrative or other public authority and not be allowed to leave. Moreover, many of the residents of the long-stay institutions that are still prevalent in Central and Eastern Europe are likely to be de facto detained, even if this is not as a result of a formal judicial or administrative decision (this is discussed below).

Although the situation of prisoners falls outside the scope of this report, the human rights standards relating to them will be referred to where it is thought helpful to make a comparison between the standards for prisoners and those relating to children, older people and persons with disability receiving formal care.
II. Key human rights principles

This chapter highlights some key principles that are common to many of the human rights standards relating to children, older people and people with disabilities.

A. EQUALITY AND NON-DISCRIMINATION

In general terms, equality is a key principle with regard to access to services, education, employment, social security and health care as well as in terms of family life and personal integrity, culture, recreation and sports, as well as religion.  

Protection against discrimination is a fundamental right that is included in all major international and European treaties. For example, the CESCR explains that “non-discrimination is an immediate and cross-cutting obligation” in the International Covenant on Economic, Social and Cultural Rights (ICESCR). States are required to guarantee non-discrimination in the exercise of each of the economic, social and cultural rights enshrined in the Covenant. Noting that similar definitions are provided in other United Nations human rights instruments, the CESCR continues:

... discrimination constitutes any distinction, exclusion, restriction or preference or other differential treatment that is directly or indirectly based on the prohibited grounds of discrimination and which has the intention or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of Covenant rights. Discrimination also includes incitement to discriminate and harassment.

The CESCR also stresses that in order to “eliminate substantive discrimination, States parties may be, and in some cases are, under an obligation to adopt special measures to attenuate or suppress conditions that perpetuate discrimination”. The need to undertake positive measures to counter existing discrimination against certain groups of people is reflected in article 5 (4) of the CRPD which provides that “[s]pecific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered to be discrimination under the terms of the... Convention”.

Taking action to address discrimination is of great importance given that there will be a wide diversity of people within the groups of children, persons with disabilities and older persons placed in formal care settings. Some are likely to be vulnerable to discrimination and other human rights violations. For example, the United Nations Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment (hereafter “Special Rapporteur on torture”) has commented that “children in detention are even at a higher risk of abuse and ill-treatment than adults” while “other highly vulnerable groups are persons with disabilities, both in general detention facilities and in psychiatric institutions; persons with diseases, such as tuberculosis or HIV/AIDS; drug addicts; the elderly....”

B. IMPORTANCE OF THE FAMILY

Many of the human rights treaties make specific reference to the importance of the family.

By way of example, article 10 (1) of the ICESCR provides that “the widest possible protection and assistance should be accorded to the family, which is the natural and fundamental group unit of society, particularly for its establishment and while it is responsible for the care and education of dependent children”. The International Covenant on Civil and Political Rights (ICCPR) in article 23 (1) includes a similar provision. Article 9 (1) of the Convention on the Rights of the Child (CRC) provides that “States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine... that such separation is necessary for the best interests of the child”.

Similar provisions exist in treaties of the Council of Europe. For example, article 16 of the European Social Charter (revised) (the right of the family to social, legal and economic protection) seeks to ensure “the
necessary conditions for the full development of the family”. 32

C. PROMOTING AUTONOMY

The importance of autonomy is reflected in a range of United Nations and Council of Europe instruments. Significantly, the CRPD places autonomy within the first of the general principles listed in article 3, namely: “Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons.” Article 12 of the CRPD also has strong links with the idea of autonomy. The Thematic Study on the CRPD notes that the Convention requires States parties to “recognize persons with disabilities as individuals before the law, possessing legal capacity, including capacity to act, on an equal basis with others”, and also to “provide access by persons with disabilities to the support they might require in exercising their legal capacity and establish appropriate and effective safeguards against the abuse of such support” (para. 43).

The Committee on the Rights of the Child emphasizes the importance of the right of all children to be heard and taken seriously contained in article 12, one of the fundamental values of the Convention. 33 Article 12 (1) provides that “States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child”.

Similarly, the Council of Europe emphasizes the importance of the principle of autonomy. The European Court of Human Rights has held that the right to self-determination and the notion of personal autonomy are inherent to the right to private and family life under article 8 of the European Convention. 34 The Council of Europe Committee of Ministers recommendation on ageing and disability identifies the promotion of autonomy and an independent active life for ageing persons with disabilities and older persons with disabilities as a key area of work, setting out a range of actions to help achieve this objective. 35

D. LEAST RESTRICTIVE ALTERNATIVE

The principle of proportionality is a key concept in human rights law. For example, in general comment No. 31 (2004) on the nature of the general obligation imposed on States parties to the Covenant, the Human Rights Committee states that where restrictions on the rights under the ICCPR have been made, “States must demonstrate their necessity and only take such measures as are proportionate to the pursuance of legitimate aims in order to ensure continuous and effective protection of Covenant rights. In no case may the restriction be applied or invoked in a manner that would impair the essence of a Covenant right” (para. 6).

Any interference with a right under the ECHR must be no more than necessary to achieve the intended (lawful) objective and must not be arbitrary or unfair. Where there has been interference with a right, the European Court of Human Rights will consider whether there were any other less restrictive actions that could have been taken.

For example, in the case of Kutzner v. Germany, which concerned the removal of children from their parents, the Court questioned whether the public authorities had given adequate consideration to providing the parents with additional measures of support, rather than taking “by far the most extreme measure” of separating the children from their parents. The Court concluded that although the authorities’ reasons for removing the children were relevant (they had legitimate concerns about the late development of the children), “they were insufficient to justify such a serious interference in the applicants’ family life.... the interference was therefore not proportionate to the legitimate aims pursued”. 37

E. PARTICIPATION

The importance of participation in the development of law and policy is emphasized by both United Nations and Council of Europe human rights instruments. For example:

- Article 25 of the ICCPR recognizes the right of individuals to “take part in the conduct of public
affairs”, to vote and to have equal access to public service.\textsuperscript{38} The Human Rights Committee points out that “the conduct of public affairs” is a broad concept that includes “the formulation and implementation of policy at international, national, regional and local levels” and the right to participate in the conduct of public affairs “should be established by the constitution and other laws”.\textsuperscript{39}

- The Committee on the Rights of the Child highlights the duty placed on States by article 12 of the Convention (Respect for the views of the child) to ensure meaningful engagement with children in policy development. The Committee considers that article 12 “requires consistent and ongoing arrangements”. The involvement of and consultation with children “must also avoid being tokenistic and aim to ascertain representative views”.\textsuperscript{40}

- In addition to providing the right to participate in political and public life under article 29, article 4 (3) of the CRPD requires States to “closely consult with and actively involve persons with disabilities” in the development and implementation of legislation and policies that impact upon them.

- “Ageing persons with disabilities and older persons with disabilities should be fully and directly involved throughout the process of designing, implementing and evaluating services. Families, care providers and friends should also be involved in these processes, as appropriate.”\textsuperscript{41}

F. INTERNATIONAL COOPERATION

The importance of international cooperation to help States realize the objectives of the particular human rights treaty is specifically provided for in the ICESCR (art. 2) and the CRPD (art. 32). The CRC refers to States encouraging and promoting international cooperation in relation to children with disabilities (art. 23) and the right to the highest attainable standard of health (art. 24). Similarly, article 4 of the Political Declaration and Madrid International Plan of Action on Ageing, 2002 emphasizes that enhanced international cooperation is essential.
III. Placements in formal care settings: the basis for intervention

A. OVERVIEW

This chapter considers the human rights aspects of the decision to place a person in a formal care setting. It highlights areas in which human rights standards are inconsistent and therefore merit further consideration.

The placing of individuals in institutional care is likely to engage a range of human rights, including the right to liberty, the right to private and family life and the right to community living. This chapter considers the right to liberty and related rights, namely the right to a review of the placement and the right to legal assistance in challenging the lawfulness of detention, as well as various standards governing the admission procedure. Specific issues relating to the decision to place children in formal care (also referred to as “alternative care” in relation to children) are also considered. The right to private and family life and the right to community living are considered in subsequent chapters.

B. THE RIGHT TO LIBERTY

Under international and European human rights law, a person cannot be deprived of his or her liberty unlawfully or arbitrarily and any deprivation of liberty must be in accordance with procedures established by law. While the wording differs slightly, these principles are common to all of the relevant articles (article 9 of the ICCPR, article 14 of the CRPD, article 37 of the CRC and article 5 of the ECHR).

The decision to deprive a person of his or her liberty is a very serious matter. By way of example, the European Court of Human Rights considers that this will only be justified under article 5 of the ECHR if other, less severe measures have been considered and found to be insufficient.

The definition of “deprivation of liberty” (also referred to as “detention”) and the circumstances in which detention is justified are discussed below.

1. Definition of “deprivation of liberty”

No definition of “deprivation of liberty” is included in article 9 of the ICCPR, article 37 of the CRC or article 14 of the CRPD. However, the Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, defines deprivation of liberty as “any form of detention or imprisonment or the placement of a person in a public or private custodial setting which that person is not permitted to leave at will by order of any judicial, administrative or other authority” (art. 4 (2)).

Although “deprivation of liberty” is not defined in article 5 of the ECHR, there is extensive jurisprudence on this issue. In assessing whether a person is detained, the European Court of Human Rights will take a range of factors into account. These include the “type, duration, effects and manner of implementation of the measure in question”. Individuals may be deprived of their liberty even if they do not resist their placement or are permitted to leave the facility on frequent occasions.

Thus, the European Court of Human Rights recognizes that a person may be de facto detained even if no order has been given by a judicial, administrative or other public authority. This is important because if a person is not deemed to be deprived of his/her liberty, certain safeguards will not apply. For example, as discussed below, under article 9 (4) of the ICCPR, article 37 (d) of the CRC and article 5 (4) of the ECHR, individuals who are detained have the right to an independent review of the decision to detain them. It is also of particular significance to the system of guardianship that is used in many parts of the world, including in Europe. This is considered below.
2. Guardianship and deprivation of liberty

In countries where a system of guardianship allows decisions to be made by the guardian on behalf of a person deemed to lack capacity, the decision to admit the person may have been made without the person’s consent. That this practice raises serious human rights concerns was highlighted in a report of the United Nations Secretary-General on progress of efforts to ensure the full recognition and enjoyment of the human rights of persons with disabilities. The report noted that the “right to recognition as a person before the law is often neglected in the context of mental health” and that the “concept of guardianship is frequently used improperly to deprive individuals with an intellectual or psychiatric disability of their legal capacity without any form of procedural safeguards”. By way of example, guardianship “may be improperly used to circumvent laws governing admission in mental health institutions”. Furthermore, “the lack of a procedure for appealing or automatically reviewing decisions concerning legal incapacity could then determine the commitment of a person to an institution for life on the basis of an actual or perceived disability”.

The concern that guardians can authorize their wards’ admission to psychiatric hospitals, thereby circumventing the procedures and safeguards under mental health law, was illustrated in Shukaturov v. Russia, which concerned a man who had been placed in a psychiatric hospital on the authority of his guardian. The European Court of Human Rights held that he had been detained. This was because the applicant was “confined to hospital for several months, he was not free to leave and his contacts with the world were seriously restricted”. The Court concluded that the applicant was detained despite the fact that under domestic law he was considered to be “voluntarily confined” (as his guardian had authorized the admission to the psychiatric hospital). In the Court’s view, the applicant’s status in national law was not relevant to the question of whether the situation amounted to a deprivation of liberty under the ECHR.

The situation of people who are deemed to lack capacity is considered in Council of Europe Committee of Ministers Recommendation Rec(2004)10, which recommends that member States should ensure that “appropriate provisions” exist to protect persons “with mental disorder” who lack the capacity to consent, are considered in need of a placement and do not object to the placement (art. 26). However, Rec(2004)10 does not address the concern that guardianship may be improperly used to authorize the admission of a person deemed to lack capacity, which may in effect amount to a deprivation of liberty.

These issues require urgent attention. It is essential that the action taken to address them are undertaken in the light of the CRPD, which has come into force since Rec(2004)10 was issued. This is because such practice infringes not only individuals’ right to liberty, but also article 12 of the CRPD (Equal recognition before the law). Article 12 requires that States parties “recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” and that they “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity” (art. 12 (2) and (3)). It also places an obligation on States parties to support persons with disabilities in exercising their legal capacity. OHCHR has recommended that the review and reform of guardianship laws be prioritized by States.

3. Clarifying the circumstances in which detention is justified

Article 5 of the ECHR permits a person to be deprived of his or her liberty only in limited and specified circumstances. It allows a person to be deprived of his or her liberty if he or she is “of unsound mind” (a term which includes “mental health problems” and “intellectual disabilities”), but only if three minimum conditions are met: that objective medical evidence has shown that the person has a mental disorder; that this is of a nature or degree warranting compulsory confinement; and the person can be detained only so long as such mental disorder persists.

The MI Principles concern the care and treatment of people of any age who are “receiving mental health care”, including “all persons who are admitted to a mental health facility”. Principle 16 provides for the circumstances in which persons can be admitted involuntarily to a mental health facility. Crucially, principle 16 permits persons to be detained on the basis of their mental disorder, subject to other conditions including that “because of that mental illness, there is a serious likelihood of immediate or imminent harm to that person or other persons”. However, OHCHR considers that this provision is in direct conflict with article 14 (1) (b) of the CRPD, which states that “the existence of a disability shall in no case justify a deprivation of liberty”.
OHCHR explains the reasons for this conclusion as follows. Whereas before the CRPD came into force, “the existence of a mental disability represented a lawful ground for deprivation of liberty and detention under international human rights law”, the CRPD “radically departs from this approach by forbidding deprivation of liberty based on the existence of any disability, including mental or intellectual, as discriminatory”. This means that unlawful detention will include situations where “the deprivation of liberty is grounded in the combination between a mental or intellectual disability and other elements such as dangerousness, or care and treatment”. Accordingly, OHCHR recommends that legislation “authorizing the institutionalization of persons with disabilities on the grounds of their disability without their free and informed consent” be abolished. This will include the repeal of provisions authorizing the institutionalization of persons with disabilities for their care and treatment without their free and informed consent. It also includes “provisions authorizing the preventive detention of persons with disabilities on grounds such as the likelihood of them posing a danger to themselves or others, in all cases in which such grounds of care, treatment and public security are linked in legislation to an apparent or diagnosed mental illness”. OHCHR explains that “this should not be interpreted to say that persons with disabilities cannot be lawfully subject to detention for care and treatment or to preventive detention, but that the legal grounds upon which restriction of liberty is determined must be de-linked from the disability and neutrally defined so as to apply to all persons on an equal basis”.  

C. REVIEW OF THE APPROPRIATENESS OF THE PLACEMENT

1. Right to challenge the lawfulness of detention

Article 9 of the ICCPR provides that anyone who is deprived of his or her liberty has a right to “take proceedings before a court in order that that court may decide without delay on the lawfulness of his detention and order his release if the detention is not lawful”. The ECHR and the CRC contain similar provisions.

2. Right to periodic reviews of detention or placement

In relation to persons detained under article 5 (4) (e) (on the grounds of “unsound mind”), the ECHR requires that there be periodic review of the lawfulness of a person’s detention by an independent judicial body.

Article 25 of the CRC requires that a periodic review be carried out in all cases where a child has been placed away from home “by the competent authorities for the purposes of care, protection or treatment of his or her physical or mental health” (it therefore applies whether or not the child is considered to be detained). The Committee on the Rights of the Child states that whatever form of placement is chosen for children with disabilities by the competent authorities, it is essential that “a periodic review of the treatment provided to the child, and all other circumstances relevant to his or her placement, is carried out to monitor his or her well-being”.

The Guidelines for Alternative Care of Children state: “It is the role of the State, through its competent authorities, to ensure the supervision of the safety, well-being and development of any child placed in alternative care and the regular review of the appropriateness of the care arrangement provided” (para. 5).

Council of Europe Committee of Ministers Recommendation Rec(2005)5 of the Committee of Ministers to member states on the rights of children living in residential institutions (hereafter “Rec(2005)5”) also recommends that there be a periodic review of a child’s placement. It also states that the child’s best interests should be the primary consideration during his or her placement and that “the parents should be supported as much as possible with a view to harmoniously reintegrating the child in the family and society”.

D. RIGHT TO LEGAL ASSISTANCE FOR PERSONS DEPRIVED OF THEIR LIBERTY

The right to seek legal assistance in challenging the lawfulness of detention is an important right for individuals who are deprived of their liberty, although few human rights instruments make specific reference to this.
In relation to children, article 37 (d) of the CRC states that every child who is deprived of his or her liberty “shall have the right to prompt access to legal and other appropriate assistance”.

The European Court of Human Rights considers that, save for “special circumstances”, persons “of unsound mind” who are deprived of their liberty should “receive legal assistance in subsequent proceedings relating to the continuation, suspension or termination of their detention”. Article 25 of Rec(2004)10 requires States to ensure that “persons with mental disorder” who are subject to involuntary placement or involuntary treatment can effectively exercise their right to appeal against the decision, to have the lawfulness of the measure reviewed by a court at reasonable intervals and “to be heard in person or through a personal advocate or representative at such reviews or appeals.” Paragraph 25 (3) highlights the importance of legal representation and the provision of public funding for this for such assistance: “Member states should consider providing the person with a lawyer for all such proceedings before a court. Where the person cannot act for him or herself, the person should have the right to a lawyer and, according to national law, to free legal aid. The lawyer should have access to all the materials, and have the right to challenge the evidence, before the court.”

E. PROCEDURES ON ADMISSION

This section highlights a range of additional procedural requirements in relation to a person’s admission and continuing placement in a formal care setting, which are set out in human rights standards. These have been identified in standards concerning prisoners, persons deprived of their liberty, children and persons receiving mental health care.

1. Evidence of authority for detention

Standards concerned with prisoners and others who are deprived of their liberty emphasize the importance of providing evidence of the authority for the person’s placement on admission. For example, Recommendation Rec(2006)2 of the Committee of Ministers to member States on the European Prison Rules (hereafter “the European Prison Rules”) state: “No person shall be admitted to or held in a prison as a prisoner without a valid commitment order, in accordance with national law” (para. 14).

Save for the reference Rec(2004)10 on the need to document the decision to detain and to “state the maximum period beyond which, according to law, they should be formally reviewed” (para. 20 (3)), the standards relating to children, persons with disabilities and older persons considered in this study do not include such a requirement. However, the Guidelines on Alternative Care highlight the importance of establishing rigorous screening procedures to ensure that children are only admitted to formal care settings when this is considered to be appropriate for that child (para. 125).

2. Separation of categories of individuals in custody or care

The requirement to separate certain categories of individuals in custody or care is highlighted in a number of human rights standards. For example the ICCPR and other instruments state that accused juveniles shall be separated from adults.

The CRC makes specific provision for children who are deprived of their liberty (this would include juvenile offenders and young people in mental health facilities) to protect them from abuse and exploitation by adults. Article 37 (c) states that “every child deprived of liberty shall be separated from adults unless it is considered in the child’s best interests not to do so”. Such children shall also “have the right to maintain contact with his or her family through correspondence and visits, save in exceptional circumstances”.

The Guidelines for Alternative Care highlight the need to take measures, “where necessary and appropriate” for children involved in criminal justice proceedings to be separated from those who have been placed in formal care for protection and alternative care” (para. 124).
3. Register of all detainees/residents

Standards relating to prisoners, juveniles deprived of their liberty, and children in formal care require that a record be kept of each person admitted to the facility.

In relation to children in formal care, the Guidelines on Alternative Care require that the records for each child should be “complete, up to date, confidential and secure”. It should include information on the child’s “admission and departure and the form, content and details of the care placement of each child, together with any appropriate identity documents and other personal information. This record should “follow the child throughout the alternative care period and be consulted by duly authorized professionals responsible for his/her current care” (para. 110).

4. Medical examination on admission

A common requirement in the human rights standards relating to prisoners and others deprived of their liberty is that they be given a medical examination as soon as they have been admitted to a prison or place of detention. This does not appear to be reflected in standards relating to children, persons with disabilities or older persons.

Guidance issued by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (known as the CPT) in relation to the care and treatment of persons deprived of their liberty (referred to in this report as “the CPT Standards”) also cover this issue. The CPT Standards state that individuals should be seen by a doctor or nurse on admission and that access to a doctor should be available at anytime.

5. Provision of information on admission

The importance of providing individuals deprived of their liberty with information relevant to their detention on admission is emphasized in a range of human rights standards. For example, under article 9 (1) of the ICCPR and article 5 (2) of the ECHR, a person has a right to be informed promptly, in a language he or she can understand, of the reasons for detention.

Similarly, standards relating to persons receiving mental health care include the provision of information on admission. For example, principle 16 of the MI Principles provide that individuals deprived of their liberty are to be informed of the grounds for the decision to detain them.

Principle 12 of the MI Principles states that individuals are to be informed of their rights “as soon as possible after admission, in a form and a language which the patient understands”. Such information shall include an explanation of those rights and how to exercise them. However, there is little emphasis on providing support to help the person understand the information. Principle 12 (2) states that if (and so long as) the person is unable to understand the information, the person’s rights are to be communicated to his/her personal representative or to the person(s) “best able to represent the patient’s interests and willing to do so”. However, the CPT Standards state that assistance should be given to any patient who is unable to understand the information. They also state that on admission a brochure setting out the establishment’s routine and patients’ rights should be given to patients and their families.

6. Information to others

The human rights standards in relation to children in alternative care and persons placed in mental health care highlight the need to keep families and other key individuals, such as legal representatives, informed of important matters concerning the detainee. For example, the Guidelines on Alternative Care suggest that parents and guardians can be given access to their child’s records, “within the limits of the child’s right to privacy and confidentiality, as appropriate” (para. 111). Both Rec(2004)10 and the MI Principles provide that information about the person’s rights should be given to their personal representative.
F. PLACEMENT OF CHILDREN IN ALTERNATIVE CARE

The Council of Europe emphasizes that placing a child away from his or her family should only happen in exceptional circumstances. Committee of Ministers Recommendation CM/Rec(2010)2 on deinstitutionalisation and community living of children with disabilities (hereafter “CM/Rec2010)2”) states: “In exceptional circumstances (for example where there has been abuse or neglect), when a child cannot live in his or her own family or a foster family, small, homely settings, that are as near to the family environment as possible, should be provided as an alternative to institutionalized forms of care” (para. 112).

Article 9 of the CRC states that children should not be separated from their parents against the will of their parents “except when competent authorities subject to judicial review” determine that this necessary in the best interests of the child.  

The Committee on the Rights of the Child “urges States parties to use the placement in institution only as a measure of last resort, when it is absolutely necessary and in the best interests of the child”. The Committee also stressed that young children should never be institutionalized solely on the grounds of disability, adding that “it is a priority to ensure that they have equal opportunities to participate fully in education and community life, including by the removal of barriers that impede the realization of their rights”.  

The Guidelines for Alternative Care state that decisions “on alternative care in the best interests of the child should take place through a judicial, administrative or other adequate and recognized procedure, with legal safeguards, including, where appropriate, legal representation on behalf of children in any legal proceedings”. Furthermore the decision “should be based on rigorous assessment, planning and review, through established structures and mechanisms, and should be carried out on a case-by-case basis, by suitably qualified professionals in a multidisciplinary team, wherever possible. It should involve full consultation at all stages with the child, according to his/her evolving capacities, and with his/her parents or legal guardians” (para. 57).

The Guidelines for Alternative Care emphasize that the use of residential care should be limited to cases where “such a setting is specifically appropriate, necessary and constructive for the individual child concerned and in his/her best interests”. In relation to young children, “especially those under the age of 3 years”, alternative care “should be provided in family-based settings” (paras. 21 and 22). They also stress that “poverty, or conditions directly and uniquely imputable to such poverty, should never be the only justification for the removal of a child from parental care, for receiving a child into alternative care, or for preventing his/her reintegration, but should be seen as a signal for the need to provide appropriate support to the family” (para. 15).
IV. Consent to treatment

A. OVERVIEW

This chapter considers human rights standards that are relevant to medical treatment decisions. The right to make one’s own treatment decisions is an important issue for everyone, including children, persons with disabilities and older persons. It is of particular relevance to mental health care given that legislation in many countries permits, in certain circumstances, persons with “mental disorder” to be treated without their consent.

The introduction of the CRPD highlights the need for further analysis on issues concerning treatment without consent. This is because, as noted by the United Nations Special Rapporteur on the right to health, the CRPD “reaffirms that the existence of a disability is not lawful justification for any deprivation of liberty, including denial of informed consent”.

While the CRPD is concerned with the rights of people with disabilities, the issues that are raised by the CRPD will be of relevance to many groups of people, in particular those that are susceptible to being treated without their consent. For example, the concept of “informed consent” will be as relevant to children with sufficient maturity to understand matters relating to their treatment and care as to adults. Furthermore, the Special Rapporteur on the right to health notes that children in institutions are “particularly vulnerable to non-consensual medical interventions” and older persons in hospice care are especially vulnerable to “non-consensual drug therapy”.

Although human rights standards emphasize the importance of respecting individuals’ autonomy in relation to decisions about their care and treatment, and that treatment without consent can only be given in exceptional circumstances, there is little clarity on when such circumstances arise. Accordingly, the recommendation by the Special Rapporteur on torture that States “issue clear and unambiguous guidelines in line with the CRPD on what is meant by ‘free and informed consent’”, if complied with by States, remains highly relevant.

B. HUMAN RIGHTS AND CONSENT TO TREATMENT

Issues relating to consent to treatment engage a range of human rights, such as the right to the highest attainable standard of health, the right to private and family life and the prohibition of torture and inhuman or degrading treatment or punishment.

For example, the application of treatment without the person’s consent will engage article 8 of the ECHR which provides that “Everyone has the right to respect for his private and family life, his home and his correspondence”. This is a wide-ranging right and in the view of the European Court of Human Rights in Pretty v. The United Kingdom, “the imposition of medical treatment, without the consent of a mentally competent adult patient, would interfere with a person’s physical integrity in a manner capable of engaging the rights protected under Article 8”.

Furthermore, the European Court of Human Rights has held that treatment without consent may, in some circumstances, give rise to a violation of article 3 of the ECHR (freedom from torture and inhuman or degrading treatment or punishment). The Special Rapporteur on torture has made similar comments in relation to article 7 of the ICCPR (prohibition of torture) and treatment without consent: “Whereas a fully justified medical treatment may lead to severe pain or suffering, medical treatments of an intrusive and irreversible nature, when they lack a therapeutic purpose, or aim at correcting or alleviating a disability, may constitute torture and ill-treatment if enforced or administered without the free and informed consent of the person concerned.”

Treatment without consent is also relevant to the right to the highest attainable standard of health under article 12 of the ICESCR. CESCR states that this right includes an obligation to refrain from applying coercive medical treatments “unless on an exceptional basis for the treatment of mental illness or the prevention and control of communicable diseases”. It goes on to state that such exceptional cases “should be subject
to specific and restrictive conditions, respecting best practices and applicable international standards, including the [MI Principles]. “

However, there is no clarification on what are considered to be “best practices” or “applicable international standards”. The reference to the MI Principles is also problematic. As noted earlier in this report, the MI Principles have been subject to strong and widespread criticism. Their continued validity is also called into question in the light of the CRPD. For example, in relation to consent to treatment, the Special Rapporteur on torture notes that the MI Principles permit involuntary treatment and that this “runs counter” to the provisions of the CRPD (such as article 25 which “recognizes that medical care of persons with disabilities must be based on their free and informed consent”). Given that reference continues to be made to the MI Principles in documents concerning consent to treatment, some of the key criticisms of the MI Principles are outlined below. Specific issues concerning children, older persons and all persons with disabilities are also discussed.

C. CHILDREN

Article 12 of the CRC (Respect for the views of the child) is of great significance to issues relating to consent to treatment for children. The Committee on the Rights of the Child considers that “the right of all children to be heard and taken seriously constitutes one of the fundamental values of the Convention”, being one of the four general principles alongside the right to non-discrimination, the right to life and development, and the primary consideration of the child’s best interests.

There is no age limit on the right of the child to express his or her own views. The Committee on the Rights of the Child explains that the phrase “capable of forming his or her own views” requires States parties “to assess the capacity of the child to form an autonomous opinion to the greatest extent possible”. A child should be presumed to have the capacity to form her or his views and express them: “it is not up to the child to first prove her or his capacity” and children should be “included in the decision-making processes, in a manner consistent with their evolving capacities”. The Committee considers that States should enact laws or regulations to ensure that confidential advice concerning treatment is provided to adolescents so that they can give their informed consent, and provide training for health personnel on the rights of adolescents to privacy and confidentiality, to be informed about planned treatment and to give their informed consent to treatment.

The recently adopted European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families highlights the importance of ensuring that children and young people with intellectual disabilities are supported to be involved in decision-making about their lives, including in relation to their individual plans for care, education and employment. The Action Plan adopted to give effect to the Declaration states that: “Children and young people with intellectual disabilities can and will contribute to decision-making about their lives, if the will to listen is present and if time, skills, resources and adaptations to procedures and policies are dedicated to ensuring their involvement”. The Declaration recognizes that to facilitate this, accessible information must be made available and that relevant policies and strategies produced “in easy-to-understand formats so that children and young people with intellectual disabilities and their families know their rights and entitlements”.

D. PERSONS WITH DISABILITIES

In considering consent to treatment in relation to people with disabilities, three rights under the CRPD will be of particular relevance: article 12 (Equal recognition before the law), article 17 (Protecting the integrity of the person) and article 25 (Health), which includes the requirement that health professionals provide care of the same quality to persons with disabilities as to others, “including on the basis of free and informed consent”. Article 15 (Freedom from torture or cruel, inhuman or degrading treatment or punishment) and article 16 (Freedom from exploitation, violence and abuse) may also be relevant.

The CRPD Committee is responsible for monitoring the implementation of the CRPD and has identified consent to treatment as an area of particular interest. For example, States parties are asked to include the following subjects in their periodic reports on the implementation of the CRPD:
• Measures taken to protect persons with disabilities from medical (or other) treatment given without the free and informed consent of the person

• Legislative and other measures to ensure that any health treatment is provided to persons with disabilities on the basis of their free and informed consent

The Special Rapporteur on the right to health considers that policies and legislation that sanction “non-consensual treatments lacking therapeutic purpose or aimed at correcting or alleviating a disability” amount to a violation of the right to physical and mental integrity and “may constitute torture and ill-treatment”. He emphasizes the obligation on States parties to “provide persons with disabilities equal recognition of legal capacity, care on the basis of informed consent, and protection against non-consensual experimentation.”

**E. PERSONS PLACED IN MENTAL HEALTH FACILITIES**

Despite the emphasis on the right of persons to give consent to proposed treatment, some human rights standards permit persons receiving mental health care to be given treatment without their consent. This has given rise to significant concerns.

For example, the Special Rapporteur on torture has raised serious concerns in relation to the practice of administering various treatments for mental disorder without the person’s consent. He also considers that “the administration in detention and psychiatric institutions of drugs, including neuroleptics that cause trembling, shivering and contractions and make the subject apathetic and dull his or her intelligence, has been recognized as a form of torture.”

The United Nations MI Principles

Principle 11 of the MI Principles states that no treatment shall be given to a person without his or her consent, but this right to consent (and, accordingly, to refuse) treatment is subject to extensive exceptions set out in the subsequent paragraphs. The conditions in which treatment can be given without consent under the MI Principles are complex. However, in essence they provide that a person who is an involuntary patient can be given treatment without his or her consent if “an independent authority” considers that the person lacks capacity to make the decision, or “having regard to the patient’s own safety or the safety of others, the patient unreasonably withholds such consent” and the treatment is considered to be in the patient’s best interests. Principle 11 also sets out the circumstances in which the patient’s personal representative can give consent and the basis on which emergency treatment can be given without the person’s consent.

The 2003 report of the Secretary-General on progress of efforts to ensure the full recognition and enjoyment of the human rights of persons with disabilities concluded that the “generous exceptions” to the right to informed consent contained in principle 11 “deprive it of real meaning”. Similar comments were made by the Special Rapporteur on the right to health in 2005. He stressed the need for procedural safeguards protecting the right to informed consent to be “both watertight and strictly applied”. In the light of the failings of the MI Principles, he recommended that “this important issue [be] given urgent reconsideration with a view to better protecting, at the international and national levels, the right to informed consent”.

Council of Europe human rights standards specific to consent to treatment

Human rights standards emanating from the Council of Europe, such as Rec(2004)10, also specify the circumstances in which persons considered to have a “mental disorder” can be treated without their consent.

Consent to treatment is included in the Convention for the Protection of Human Rights and Dignity of the Human Being with the Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, 1997. Although article 5 provides that a health-care intervention may only be given with the person’s “free and informed consent” and the person may “freely withdraw consent at any time”, this is subject to exceptions, some of which will have an impact on persons deemed to have a “mental disorder”. One of the exceptions to this rule is that a person with a mental disorder of a serious nature can be given treatment for the mental disorder, but “only where, without such treatment serious harm is likely to result to his or her health.”
The CPT Standards emphasize the importance of enabling people to make decisions about their own treatment, pointing out that “the admission of a person to a psychiatric establishment on an involuntary basis should not be construed as authorising treatment without his consent”, adding that it “follows that every competent patient, whether voluntary or involuntary, should be given the opportunity to refuse treatment or any other medical intervention”. Nonetheless, the CPT Standards anticipate that there may be circumstances in which treatment can be given without consent. Although stating that any derogation from the “fundamental principle” of free and informed consent “should be based upon law and only relate to clearly and strictly defined exceptional circumstances”, no further information on when and how such exceptional circumstances might arise is provided.\textsuperscript{107}

F. OLDER PERSONS

The particular issues for older persons and consent to treatment are gaining greater attention. For example, in 2009, the Special Rapporteur on the right to health raised concerns that “support structures protecting the rights of elderly persons are grossly inadequate” and that elderly persons in hospice care “are especially vulnerable to denial of autonomy and dignity”.\textsuperscript{108} He pointed out that States are required to ensure that older persons enjoy the right to health, including informed consent, at the same level as any other person and recommended that “international guidelines and national systems should be developed to regulate and monitor hospice care practices to ensure that the elderly are supported in making informed health-care decisions, and that their human dignity and autonomy are not neglected due to their vulnerability.”\textsuperscript{109}

In 2010, having noted the lack of respect for the right of older women to self-determination and consent regarding health care, the Committee on the Elimination of Discrimination against Women (CEDAW) recommended that health policies must also ensure that health care provided to older women, including those with disabilities, is based on the free and informed consent of the person concerned.\textsuperscript{110}
V. Monitoring the rights of individuals in formal care settings

A. OVERVIEW

This chapter provides an overview of United Nations and Council of Europe human rights standards that require States to monitor and safeguard the rights of individuals who are placed in the custody and/or care of the State. This includes individuals who are placed in institutional care, as well as those living in community-based residential care settings. In order to comply with this duty, States are required to establish systems to monitor and review so that the rights of those living in formal care settings are respected. The range of areas that will need to be addressed in such systems are considered in chapter VI.

States have a general duty to protect the human rights of all their citizens. A range of United Nations and Council of Europe human rights standards require that States put in place appropriate safeguards to monitor and ensure that the rights of individuals in the custody and/or care of the State are respected. For example, the Human Rights Committee has drawn attention to the need to put in place “safeguards for the special protections of particularly vulnerable persons”. Furthermore, the objective of the Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment is to “establish a system of regular visits undertaken by independent international and national bodies to places where people are deprived of their liberty, the aim being to prevent cruel, inhuman or degrading treatment”.

Such standards will be relevant to all persons who are currently placed in institutional care, as well as those living in community-based residential care settings.

B. CHILDREN IN ALTERNATIVE CARE

The Convention on the Rights of the Child emphasizes the important role of States in protecting children. For example, article 19 of the Convention requires States parties to take “all appropriate” measures to protect children from “all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of... any person....” Such protective measures should include reporting, referral and instigation.

The CRC also places great emphasis on the need to protect children receiving services and support from the State. Article 20 of the CRC provides that children who are not able to stay (whether temporarily or permanently) in their family environment are entitled to special protection and assistance from the State; such placements must be subject to a periodic review under article 25.

Article 3 (3) of the CRC provides: “States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.” Article 3 therefore requires Governments to ensure that standards are developed for the range of services provided, whether by the State or by the voluntary or private sector, including standards for the quality of care and living conditions in formal settings (including institutions). This also requires independent inspection and monitoring systems to be established.

This is an area covered by the Guidelines for Alternative Care, which recommend that States ensure that all agencies involved in the provision of alternative care for children are regularly monitored and reviewed by the competent authorities (para. 92). Principles 128-130 of the Guidelines for Alternative Care include detailed recommendations on monitoring and inspection, including the need for the place in which formal care is provided to be accredited. Furthermore, regular monitoring and review is needed and authorities “should develop appropriate criteria for assessing the professional and ethical fitness of care providers and for their accreditation, monitoring and supervision” (para. 55).
Rec(2005)5 states that facilities in which children are to be placed should be “accredited and registered with the competent public authorities and legislation should stipulate that the failure to comply with such registration and authorisation requirements constitutes an offence punishable by law”.

The Parliamentary Assembly of the Council of Europe has recently issued Recommendation 1934 (2010) entitled “Child abuse in institutions: ensuring full protection of the victims”. This highlights the Assembly’s great concern about the extent to which children and adults have been abused in institutions and the lack of action by member States to address this issue. The Assembly reminds member States of Rec(2005)5, which recognizes the right of children “to respect for the child’s human dignity and physical integrity; in particular, the right to conditions of human and non-degrading treatment and a non-violent upbringing, including the protection against corporal punishment and all forms of abuse”. The recommendation sets out a raft of measures that member States should put in place through legislation, including developing and monitoring “internal guidelines for the prevention of child abuse, which are to be applied by and to all institutions without exception” and “reinforcing rules and modalities for the external supervision of various institutions” (paras. 4.2.2 and 4.2.3).  

C. PERSONS WITH DISABILITIES

In order to prevent the occurrence of “all forms of exploitation, violence and abuse”, article 16 of the CRPD provides that States must ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities. This is in addition to article 33 of the CRPD which requires States to establish mechanisms for the implementation and monitoring of the Convention at the national level.

D. INDIVIDUALS PLACED IN MENTAL HEALTH FACILITIES

Principle 8 (2) of the MI Principles states: “Every patient shall be protected from harm, including unjustified medication, abuse by other patients, staff or others or other acts causing mental distress or physical discomfort.” Principle 22 requires that States establish appropriate mechanisms for the inspection of mental health facilities and the investigation of complaints. In his report to the Human Rights Commission in 2005, the Special Rapporteur on the right to health raised concerns that despite this provision in the MI Principles, “in many countries there is an absence of sustained and independent monitoring of mental health care. All too frequent abuses of the right to health, and other human rights, go unnoticed”. He added that the “lack of surveillance is doubly problematic” because people with mental disabilities, especially those who are institutionalized, are often unable to access independent and effective accountability mechanisms when their human rights have been violated. This may be for a range of reasons such as the absence of procedural safeguards, a lack of access to legal aid, people not being aware of their rights, or because there is no independent accountability mechanism.

Rec(2004)10 highlights the importance of “quality assurance and monitoring”. Article 36 requires that member States ensure compliance with the standards set out in the recommendation and that such systems be properly resourced, be independent from the bodies being monitored, involve “mental health professionals, lay persons, persons with mental disorder and those close to such persons” and be coordinated, where appropriate, with other relevant audit and quality assurance systems. The monitoring mechanisms should include:

- Conducting visits and inspections of mental health facilities (including unannounced visits)
- Ensuring that powers exist to investigate the death of persons subject to involuntary placement or involuntary treatment, and that any such death is notified to the appropriate authority and is subject to an independent investigation
- Ensuring that complaints procedures are provided and complaints responded to appropriately

One of the key functions of the monitoring mechanism is to ensure that “persons are only subject to involuntary placement in facilities registered by an appropriate authority, and that such facilities are suitable for that function” (art. 9 (2)).
E. OLDER PERSONS

CESCR reminds States that they “are obligated to pay particular attention to promoting and protecting the economic, social and cultural rights of older persons”.124 The Committee adds that its own role in this area “is rendered all the more important by the fact that, unlike the case of other population groups such as women and children, no comprehensive international convention yet exists in relation to the rights of older persons and no binding supervisory arrangements attach to the various sets of United Nations principles in this area”.125 CESC therefore insists that future reports adequately address the situation of older persons in relation to the rights set out in the ICESCR.126

Article 23 of the European Social Charter (revised) (The right of elderly persons to social protection) includes a provision specific to older people “living in institutions”. It states that, with a view to ensuring the effective exercise of elderly persons to social protection, States will undertake to “adopt or encourage” measures designed to “guarantee elderly persons living in institutions appropriate support, while respecting their privacy, and participation in decisions concerning living conditions in the institution”.127

The Council of Europe Committee of Ministers recommendation to member states on ageing and disability in the 21st century: sustainable frameworks to enable greater quality of life in an inclusive society, highlights the role of monitoring and inspection as well as a complaints system in the work to enhance the quality of services to be established as part of this work.128
VI. Rights of residents of formal care settings

A. OVERVIEW

This chapter focuses on United Nations and Council of Europe human rights standards relevant to the care and treatment of children, persons with disabilities and older persons who are in formal care.

As discussed in chapter V, States are under a duty to safeguard the rights of individuals in formal care settings. To comply with this duty it will be necessary for States to monitor the quality of care provided to persons residing in formal care settings and to ensure that the care and treatment residents receive protects and promotes their human rights. This will require the development of standards that reflect international and European human rights standards and provide a means of assessing the day-to-day care and treatment of persons placed in such settings.

1. The need to develop standards for monitoring formal care settings

The development of such standards is an essential part of Governments’ work to develop community-based alternatives to institutional care. This is because, as noted in chapter I, during the transition from institutional care to community-based services, Governments will need to protect the rights of children, persons with disabilities and older persons who currently reside in institutions.

Governments will also need to ensure compliance with human rights standards when monitoring the situation of persons receiving community-based residential services. The need to take action to safeguard the rights of those receiving community-based services was highlighted by the Special Rapporteur on the right to health. His report on persons with mental disabilities noted that in addition to concerns about the human rights violations in institutions, there was also increasing information about violations in community-based facilities. The report added: “As countries move to community-based care and support, violations in this context will inevitably become more numerous unless appropriate safeguards are introduced.”

2. The importance of the Convention on the Rights of Persons with Disabilities

The CRPD is of particular importance not only because it makes specific provision for persons with disabilities, but also because it introduces a different approach to human rights concepts such as the emphasis on enabling individuals to live independently and participate fully in all aspects of life, through a range of measures including assistance and support. This new approach will need to be reflected in standards relating to the care and treatment of children and older persons placed in formal care settings, as well as standards relating to persons with disabilities. Accordingly, some of the areas considered in this chapter will need to be reviewed in the light of the CRPD. For example, areas that receive little attention in existing standards will need to be included, such as recognition of individuals’ right to private and family life. Other areas, such as restraint and seclusion, will require further attention in the light of concerns about human rights violations.

In this chapter reference will be made to human rights standards that concern prisoners and other persons deprived of their liberty. This is because a wide range of non-binding human rights standards have been adopted in relation to such persons. This highlights a paradox that currently exists as on the international, regional and even national levels, standards for prisoners tend to be better developed than those for other categories of persons in institutions.

The areas covered in this chapter are set out below. They reflect the common themes arising from the non-binding human rights standards concerning individuals in the care or custody of the State:

- Living conditions
- Respect for personal autonomy, family life and citizenship
• Health care
• Staffing
• Confidentiality
• Employment
• Education
• Restraint and seclusion
• Complaints and investigations
• Aftercare

For each of these areas general points will be considered, followed by examples of human rights standards that are specific to children, persons with disabilities (including those placed in mental health facilities) and older people.

B. LIVING CONDITIONS

Significant concerns have been raised by international and European human rights mechanisms about the poor living conditions in institutions for children, persons with disabilities and older persons and homes for persons with disabilities. For example, the Committee on the Rights of the Child has raised concerns about the high number of institutionalized children and the poor standard of living and quality of care in institutions in some countries. Similarly, the Explanatory Notes to Rec(2004)10 highlight concerns about the continuing failure to provide adequate care to people in psychiatric institutions: “Even today, there are reports of psychiatric facilities in Europe in which fundamental means necessary to support life (food, warmth, shelter) have not been supplied, as a result of which patients have been reported to have died from malnutrition and hypothermia. Such conditions are totally unacceptable” (para. 65).

Both article 11 of the ICESCR and article 28 of the CRPD require States to recognize the right of everyone to an adequate standard of living, including adequate food, clothing and housing. Poor living conditions may also amount to a violation of the prohibition of torture or cruel, inhuman or degrading treatment or punishment.

The non-binding human rights standards concerning the living conditions of prisoners are extensive in comparison with the few standards relating to persons receiving mental health care and children in alternative care. For example, the standards for prisoners cover a range of areas: living space, sleeping accommodation, sanitary facilities and hygiene, cleanliness and maintenance of the building, clothing, nutrition, privacy and property, and exercise and leisure.

1. Children in alternative care

Article 27 (1) of the CRC provides for the “right of every child to a standard of living adequate to the child’s physical, mental, spiritual, moral and social development”. The Guidelines for Alternative Care make various recommendations in relation to the living conditions in formal care settings for children, such as:

• Facilities providing residential care should be small and be organized around the rights and needs of the child, in a setting as close as possible to a family or small group situation (para. 123).

• Carers should ensure that children receive adequate amounts of wholesome and nutritious food in accordance with local dietary habits and relevant dietary standards, as well as with the children’s religious beliefs, and appropriate nutritional supplementation should also be provided when necessary (para. 83).
2. PERSONS WITH DISABILITIES WHO ARE DEPRIVED OF THEIR LIBERTY

Under article 14 (2) of the CRPD, States must ensure that persons with disabilities who are deprived of their liberty are entitled to “provision of reasonable accommodation”. The Special Rapporteur on torture points out that this requires, when such adjustments do not impose a disproportionate or undue burden, appropriate modifications to be made to the procedures and physical facilities of detention centres, including care institutions and hospitals, to ensure that persons with disabilities enjoy the same rights and fundamental freedoms as others. He adds: “The denial or lack of reasonable accommodations for persons with disabilities may create detention and living conditions that amount to ill-treatment and torture.”

Similarly, in Price v. The United Kingdom, the European Court of Human Rights found that article 3 of the ECHR (prohibition of torture or inhuman or degrading treatment or punishment) had been breached as a result of the failure of a prison authority to provide adequately for a prisoner with disabilities. This was despite the lack of a “positive intention to humiliate or debase” her. The Court took the view “that to detain a severely disabled person in conditions where she is dangerously cold, risks developing sores because her bed is too hard or unreachable, and is unable to go to the toilet or keep clean without the greatest of difficulty, constitutes degrading treatment, contrary to Article 3 of the Convention”.

3. PERSONS PLACED IN MENTAL HEALTH CARE FACILITIES

The scope and depth of the non-binding standards relating to the rights of persons placed in mental health care facilities vary, with the CPT Standards being the most detailed.

The MI Principles provide little guidance on the quality of living conditions in mental health facilities, save that the environment and living conditions in such facilities “shall be as close as possible to those of the normal life of persons of similar age” and should include facilities for recreational and leisure activities, for education, to purchase or receive items for daily living, recreation and communication, and for occupation and “vocational rehabilitation measures” (principle 13). They also state that mental health facilities may only receive “involuntarily admitted patients” if they have “been designated to do so by a competent authority prescribed by domestic law” (principle 16 (3)).

Council of Europe Rec(2004)10 states that the environment and living conditions should be as close as possible “to those of persons of similar age, gender and culture in the community” and that vocational rehabilitation measures “to promote the integration of these persons in the community” should also be provided (art. 9).

The CPT Standards on involuntary placement in psychiatric establishments address similar areas to those covered by the prison standards, namely: living space, sleeping accommodation, sanitary facilities and hygiene, cleanliness and maintenance of the building, clothing, nutrition, privacy and property, exercise and leisure. While they provide greater guidance on what should be expected in mental health facilities than other human rights standards, the language used is insufficiently robust, suggesting rather low aspirations for the residents of such facilities. For example, they state that the provision of bedside tables and wardrobes is “highly desirable”, whereas the CPT notes that the practice observed in some psychiatric facilities of continuously dressing patients in pyjamas/nightgowns “is not conducive to strengthening personal identity and self-esteem”. The standards also include the following points:

- Living space: Provision of accommodation structures based on small groups is a crucial factor in preserving/restoring patients’ dignity, and is a key element of any policy for the psychological and social rehabilitation of patients.
- Sleeping accommodation: Large-capacity dormitories are not compatible with the norms of modern society and “patients should be allowed to keep certain personal belongings”.
- Sanitary facilities and hygiene: The needs of elderly and/or patients with disabilities should be given due consideration; for example, lavatories of a design that does not allow the user to sit are not suitable for such patients.
• Clothing: Individualism of clothing should form part of the therapeutic process.

• Privacy and property: Patients who wish to have access to their room during the day, rather than being obliged to remain assembled together with other patients in communal areas, should be allowed to do so.

• Exercise and leisure: Patients should have regular access to suitably equipped recreation rooms and have the possibility to take outdoor exercise on a daily basis; it is also desirable for them to be offered education and suitable work.

C. RESPECT FOR PERSONAL AUTONOMY, FAMILY LIFE AND CITIZENSHIP

This section considers issues falling within the broad category of respect for personal autonomy, family life and citizenship, including maintaining personal relationships and contact with the outside world. This encompasses areas to which human rights standards relating to the care and treatment of children, persons with disabilities and older people have given insufficient attention to date.

As noted in the introduction to this report, common factors that mark institutional care are the removal of personal possessions, rigid routines that ignore personal preferences or needs, and residents having little or no contact with people outside the institution. Such barriers to personal autonomy and participation in society raise a wide range of issues such as freedom of thought, conscience and religion, cultural identity, decision-making and family life, thereby engaging numerous human rights, for example:

• Right to private and family life (article 17 of the ICCPR, article 16 of the CRC, article 22 of the CRPD and article 8 of the ECHR)

• Freedom of thought, conscience and religion (article 18 of the ICCPR, article 14 of the CRC and article 9 of the ECHR)

• Respect for the views of the child (article 12 of the CRC)

• Right of members of minorities or indigenous groups to enjoy their own culture, language and religion (article 27 of the ICCPR and article 30 of the CRC)

• Right to participate in cultural life (article 15 of the ICESCR, article 31 of the CRC and article 30 of the CRPD)

• Right to marry and found a family (article 23 of the ICCPR, article 12 of the ECHR and article 23 of the CRPD)

• Right to participate in political and public life (article 25 of the ICCPR and article 29 of the CRPD)

Except with respect to children without parental care, little attention has been given to the importance of protecting and promoting personal autonomy, family life and citizenship for individuals receiving formal care. Further consideration is therefore needed on developing standards in this area. Such standards should highlight the need for formal care settings not only to provide good quality care appropriate to each individual’s personal needs and preferences, but also to enable each person to exercise his/her rights fully and in all aspects of life.

1. Persons with disabilities

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993 provide further guidance on the issues that need to be considered. For example, rule 10 provides that “States will ensure that persons with disabilities are integrated into and can participate in cultural activities on an equal basis”; rule 11 provides that “States will take measures to ensure that persons with disabilities have equal opportunities for recreation and sports” and rule 12 stipulates that “States will encourage measures for equal participation by persons with disabilities in the religious life of their communities”. Rule 9 provides
that “States should promote the full participation of persons with disabilities in family life”.

While these rules focus on persons with disabilities, they can be applied more generally. The Rules explain that the term “equalization of opportunities” means “the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all, particularly to persons with disabilities”.

2. Children in alternative care

Article 9 (3) of the CRC provides that children who are separated from one or both parents have a right “to maintain personal relations and direct contact with both parents on a regular basis, except if it is contrary to the child’s best interests”. The Guidelines for Alternative Care include a range of measures for the provision of care that respects the individuality of each child and seeks to enable them to maintain contact with their family. For example:

- “All adults responsible for children should respect and promote the right to privacy, including appropriate facilities for hygiene and sanitary needs, respecting gender differences and interaction, and adequate, secure and accessible storage space for personal possessions” (para. 80).
- Children should be encouraged and helped to remain in contact with their families, as well as with other persons close to them, such as friends, neighbours and previous carers, “in keeping with the child’s protection and best interests”, and they should have access to information on the situation of their family members in the absence of contact with them (para. 81).
- Siblings have the right, wherever possible, to stay together or maintain regular contact (para. 17).

Rec(2005)5 states that individual care plans should be prepared which are “based on both the development of the child’s capacities and abilities and respect for his or her autonomy, as well as on maintaining contacts with the outside world and preparation for living outside the institution in the future”.

3. Persons receiving mental health care

The areas of respect for personal autonomy, family life and citizenship are given very little attention in the standards relating to the provision of mental health care. However, some key points are addressed:

- Every individual in a mental health facility has a right to the full respect of his or her freedom of communication, which includes the freedom to communicate with other persons in the facility; freedom to send and receive uncensored private communications; freedom to receive visits from their lawyer or personal representative and others; as well as freedom of access to the telephone and postal services and to newspapers, radio and television.
- Confidential access to a lawyer should also be guaranteed.
- The maintenance of contact with the outside world is essential, not only for the prevention of ill-treatment but also from a therapeutic standpoint.
- “Every patient shall have the right to treatment suited to his or her cultural background.”
- “Persons with mental disorder” are entitled to exercise their civil and political rights and any restriction on such rights must be in accordance with the ECHR and “should not be based on the mere fact that a person has a mental disorder”.

Article 30 of Rec(2004)10 raises a particular concern. It provides that the “mere fact that a person has a mental disorder should not constitute a justification for permanent infringement of his or her capacity to procreate”. The Explanatory Note states that this refers to sterilization, which “is not a treatment for mental disorder”, and that any restriction on the right to found a family would need to be in accordance with article 12 of the ECHR (the right to marry and found a family). However, the use of the word “permanent”
is ambiguous, as it suggests that temporary interventions would be acceptable. This provision would need to be clarified so as to ensure that it complies both with the ECHR and the CRPD, in particular article 23 (Respect for home and the family) and article 25 (Health).

4. Older persons

Few human rights standards include specific reference to the rights of older people in formal care. However, the following United Nations and Council of Europe non-binding human rights standards are of relevance to respect for personal autonomy, family life and citizenship:

- “Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.”

- “Living arrangements (at home, in supported accommodation or in residential placement) should take account of the individuals’ wishes and needs.”

D. PROVISION OF HEALTH CARE

The right to the “enjoyment of the highest attainable standard of physical and mental health” is set out in article 12 of the ICESCR. The CESC stresses that “health is a fundamental human right indispensible for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity”. As part of the State’s obligations to protect their citizens’ right to health, they must “ensure that medical practitioners and other health professionals meet appropriate standards of education, skill and ethical codes of conduct”.

The provision of health care is an area to which the standards on prisoners give detailed attention, emphasizing the importance of ensuring the provision of adequate medical care for prisoners. For example, rule 22 (1) of the Standard Minimum Rules for the Treatment of Prisoners requires every prison to have proper health-care facilities and to have “available the services of at least one qualified medical officer who should have some knowledge of psychiatry”. The European Prison Rules state that the prison medical service “shall provide for the psychiatric treatment of all prisoners who are in need of such treatment and pay special attention to suicide prevention”.

1. Children

Article 24 of the CRC states that children have the right to “facilities for the treatment of illness and rehabilitation of health” and that States parties “shall strive to ensure that no child is deprived of his or her right of access to such health care services”. As discussed in chapter III, article 25 of the CRC is of specific relevance to children in alternative care. It provides that every child who is placed in care has the right to a periodic review of the treatment provided and other circumstances relevant to his or her placement. This review should encompass not just the child’s health care, but also “the child’s institutional experience, including, for example, measures used to control the child, the child’s access to the outside world and how the child’s education is affected”.

The Guidelines for Alternative Care state: “Carers should promote the health of the children for whom they are responsible and make arrangements to ensure that medical care, counselling and support are made available as required” (para. 80).
2. Persons with disabilities

Article 25 of the CRPD requires States parties to “recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”. It requires States parties to “take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation” and to take measures to ensure that health professionals “provide care of the same quality to persons with disabilities as to others... by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care”.

CESCR, quoting the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, stresses that States should ensure that persons with disabilities are provided with “the same level of medical care within the same system as other members of society”.

3. Persons placed in mental health facilities

In relation to persons placed in mental health facilities, the MI Principles and standards emanating from the Council of Europe provide some guidance on the provision of health care. For example:

- All persons have the right to “the best available mental health care, which shall be part of the health and social care system”.
- Every person’s treatment and care “should be based on an individualised approach, which implies the drawing up of a treatment plan for each patient”.
- The treatment of each person “shall be directed towards preserving and enhancing personal autonomy.”
- A range of services of appropriate quality should be provided to meet the mental health, and physical health, needs of persons with mental disorder and to ensure equitable access to such services (taking into account available resources).

4. Older persons

CESCR highlights the importance of an integrated approach in relation to the realization of the right to health of older persons, combining elements of preventative, curative and rehabilitative treatment.

Principle 11 of the United Nations Principles for Older Persons states that “older persons should have access to health care to help them to maintain or regain the optimum level of physical, mental and emotional well-being and to prevent or delay the onset of illness”.

E. STAFFING

A crucial aspect of the quality of care provided to children, persons with disabilities and older persons in formal care, and for ensuring respect for their human rights and dignity, will be the quantity and quality of staff. This issue is considered in some non-binding United Nations and Council of Europe human rights standards relating to children in alternative care, persons placed in mental health facilities and older persons.

The standards fall into two broad categories: the attitude of staff and respect for human rights and the management, recruitment and training of staff. Examples of such standards in relation to children in alternative care, persons placed in mental health facilities and older people are given below.

The issue of staffing is another area in which comparison with standards for prisoners is instructive. Both United Nations and Council of Europe standards highlight the importance of staff maintaining high standards in their care of prisoners. By way of example, in addition to requiring staff to operate to high
professional and personal standards, the European Prison Rules stress the “obligation to treat all prisoners with humanity and with respect for the inherent dignity of the human person” (rule 72.1). The Standard Minimum Rules for the Treatment of Prisoners requires the prison administration to raise awareness among the public and prison personnel that their work is “a social service of great importance” (rule 46.2).

1. Children in alternative care

The Guidelines on Alternative Care state that carers “should understand the importance of their role in developing positive, safe and nurturing relationships with children, and should be able to do so” (para. 90). They also include detailed provisions on management, recruitment and training of staff. For example:

- All agencies and facilities should have written policy and practice statements “setting out clearly their aims, policies, methods and the standards applied for the recruitment, monitoring, supervision and evaluation of qualified and suitable carers to ensure that those aims are met” (para. 106).

- Training should be provided to all carers, including on “the rights of children without parental care and on the specific vulnerability of children in particularly difficult situations, such as emergency placements or placements outside their area of habitual residence” as well as in “dealing appropriately with challenging behaviour, including conflict resolution techniques and means to prevent acts of harm or self-harm” (paras. 115 and 116).

- “States should ensure that there are sufficient carers in residential care settings to allow individualized attention and to give the child, where appropriate, the opportunity to bond with a specific carer” (para. 126).

2. Persons placed in mental health facilities

The MI Principles make no specific reference to the attitudes of staff, but state in principle 1 that those receiving mental health care “shall be treated with humanity and respect for the inherent dignity of the human person”. Rec(2004)10 states that staff training should include “protecting the dignity, human rights and fundamental freedoms of persons with mental disorder” (art. 11 (2) (i)). The CPT Standards state that during the Committee’s inspections it pays close attention to “the attitudes of doctors and nursing staff”, in particular “evidence of genuine interest in establishing a therapeutic relationship with patients” (para. 44).

The CPT Standards include the management, recruitment and training of staff. For example they state that staff resources “should be adequate in terms of numbers, categories of staff (psychiatrists, general practitioners, nurses, psychologists, occupational therapists, social workers, etc), and experience and training” (para. 42). Furthermore, the Standards stress that “it is of crucial importance that auxiliary staff are carefully selected and that they receive both appropriate training before taking up their duties and in-service courses”; they should also be supervised by, and be subject to the authority of, qualified health-care staff (para. 28).162

The CPT Standards highlight “serious misgivings” about the practice in some countries of using patients or “inmates from neighbouring prison establishments as auxiliary staff in psychiatric facilities”. The CPT considered that this should be a “measure of last resort” (para. 29). This is another example where it seems that the standards relating to prisoners are more demanding than those relating to persons in formal care. This situation, if applied in relation to juvenile offenders, could well breach the European Rules for juvenile offenders subject to sanctions or measures, which state: “Budgetary constraints shall never lead to the secondment of persons who lack the necessary qualifications” (rule 134.2)

3. Older persons

In relation to attitudes of staff, the Council of Europe Committee of Ministers recommendation on ageing and disability state that the staff of support services should recognize, both in their training and in carrying out their professional duties, “the rights of those concerned to personal autonomy and choice over types, location, timing and pace of the services to be provided, when assistance with living is required”.163
F. CONFIDENTIALITY

The collection and sharing of personal information about individuals receiving formal care requires consideration of the duty of confidentiality and data protection. These issues are of direct relevance to the right to private and family life (article 17 of the ICCPR, article 16 of the CRC, article 22 of the CRPD and article 8 of the ECHR). For example article 8 (1) of the ECHR provides that “Everyone has the right to respect for his private and family life, his home and his correspondence”. The European Court of Human Rights has held that “the protection of personal data, not least medical data, is of fundamental importance to a person’s enjoyment” of the right to respect for private and family life under article 8. The Court added:

Respecting the confidentiality of health data is a vital principle in the legal systems of all the Contracting Parties to the Convention. It is crucial not only to respect the sense of privacy of a patient but also to preserve his or her confidence in the medical profession and in the health services in general.\textsuperscript{164}

1. Children in alternative care

The Guidelines on Alternative Care recommend that all alternative care services have “a clear policy on maintaining the confidentiality of information pertaining to each child, which all carers are aware of and adhere to” (para. 112). Comprehensive and up-to-date records “should be maintained regarding the administration of alternative care services”, including detailed files on all children in their care, which should be “complete, up to date, confidential and secure” (paras. 109 and 110). In addition, children in care should be “offered access to a person of trust in whom they may confide in total confidentiality” (the child “should be informed that legal or ethical standards may require breaching confidentiality under certain circumstances”) (para. 98).

2. Persons placed in mental health facilities

Principle 6 of MI Principles states that the right to confidentiality of information shall be respected. In addition to providing that personal information relating to persons with “mental disorder” should be treated as confidential and “may only be collected, processed and communicated according to the rules relating to professional confidentiality and personal data protection”, Rec(2004)10 states that “clear and comprehensive” records should be maintained (art. 13).

G. EMPLOYMENT

The right to work is set out in article 6 of the ICESCR, article 27 of the CRPD and articles 1 to 3 of the European Social Charter. For example, article 6 (1) of the ICESCR states that the right to work “includes the right of everyone to gain his living by work which he freely chooses or accepts, and [States parties] will take appropriate steps to safeguard this right”.

Principle 13 of the MI Principles refers to the use of vocational guidance and training and placement services to enable “patients to secure or retain employment in the community”. It prohibits the use of forced labour and states that “patients” shall have the same remuneration for work as would “a non-patient”. This is in stark contrast to the standards on the general care and treatment of prisoners, which contain detailed provisions concerning employment. They seek to encourage prisoners into employment,\textsuperscript{165} and “as far as possible the work provided shall be such as will maintain or increase prisoners’ ability to earn a living after release”.\textsuperscript{166} The type of work offered should include vocational training in “useful trades” to those that can benefit from it.\textsuperscript{167} Prisoners’ working hours “shall leave one rest day a week and sufficient time for education and other activities required as part of the treatment and rehabilitation of the prisoners” (rule 75).\textsuperscript{168}

H. EDUCATION

The right to education is provided for in article 13 of the ICESCR, article 24 of the CRPD, articles 28 and 29 of the CRC and article 1 of Protocol No. 11 to the ECHR.
As with employment, the standards relating to prisoners include detailed provisions on education, unlike those relating to children, persons with disabilities and older persons in formal care. Education is regarded by United Nations and European human rights standards as an important factor in the rehabilitation of prisoners. For example, the Standard Minimum Rules for the Treatment of Prisoners state that the purpose of imprisonment is to protect society, and that that “can only be achieved if the period of imprisonment is used to ensure, so far as possible, that upon his return to society the offender is not only willing but able to lead a law-abiding and self-supporting life”; to that end prisons are expected to “utilize all remedial, educational, moral, spiritual and other forces and forms of assistance which are appropriate and available, and should seek to apply them according to the individual treatment needs of the prisoners” (rules 58 and 59).

1. Children in alternative care

Although the right to education applies to all children, the Committee on the Rights of the Child is concerned that inadequate education is provided to children in “social care institutions”. It highlights the need for such children to be provided with mainstream education. The importance of education for children in alternative care is also emphasized by United Nations and Council of Europe non-binding human rights standards. For example, the Guidelines for Alternative Care state that children “should have access to formal, non-formal and vocational education in accordance with their rights, to the maximum extent possible in educational facilities in the local community” (para. 85).

2. Persons receiving mental health care

The MI Principles provide little guidance, stating only in principle 13 that facilities for education shall be included in mental health facilities. Rec(2004)10 makes specific provision for children who are placed in mental health facilities. It states that such children should have “the right to a free education and to be reintegrated into the general school system as soon as possible. If possible, the minor should be individually evaluated and receive an individualised educational or training programme” (art. 29 (5)).

I. RESTRAINT AND SECLUSION

Standards concerning the care and treatment of prisoners, other persons deprived of their liberty, and persons receiving mental health care permit the restraint and seclusion of individuals in certain circumstances. The Guidelines for Alternative Care provide guidance on the use of restraint and other means to control children (para. 97).

The Special Rapporteur on torture raised serious concerns about the use of restraint and seclusion on persons with disabilities in his interim report to the General Assembly in 2008: “Poor conditions in institutions are often coupled with severe forms of restraint and seclusion: children and adults with disabilities may be tied to their beds, cribs or chairs for prolonged periods, including with chains and handcuffs; they may be locked in ‘cage’ or ‘net beds’ and may be overmedicated as a form of chemical restraint.” The Special Rapporteur stresses that “prolonged use of restraint can lead to muscle atrophy, life-threatening deformities and even organ failure”, and exacerbates psychological damage. He “notes that there can be no therapeutic justification for the prolonged use of restraints, which may amount to torture or ill-treatment”.

The Special Rapporteur also notes that persons with disabilities are often held in seclusion or solitary confinement as a form of control or medical treatment. Referring to the Human Rights Committee’s concluding observations on the periodic reports of Slovakia and the Czech Republic (in which the Committee raised concerns about the use of cage beds as a means to restrain patients), he commented that this practice “cannot be justified for therapeutic reasons, or as a form of punishment”. The Special Rapporteur further notes that prolonged solitary confinement and seclusion of persons may constitute torture or ill-treatment.

Such comments raise serious questions about the continued use of physical restraint and seclusion. The CPT Standards note that the trend in modern psychiatric practice is in favour of avoiding seclusion (which
it defines as “confinement alone in a room”, of violent or otherwise “unmanageable” patients (para. 49). The CPT has also issued a document on the use of restraint which states that restraint should only be used in emergency situations, but “even in these cases, restraint measures should be used only as a means of last resort” and “must be the least restrictive and the most appropriate out of the available alternatives”. 175

Standards that allow the use of seclusion and restraint will need to be considered in the light of the CRPD which, in addition to prohibiting torture or cruel or degrading treatment or punishment (art. 15) and violence and abuse (art. 16), requires States parties to take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise (art. 4 (e)).

1. Children in alternative care

The Guidelines for Alternative Care provide a range of recommendations on the use of restraint.176 For example:

• All care staff should receive training in dealing appropriately with challenging behaviour, including conflict resolution techniques and means to prevent acts of harm or self-harm (para. 116).

• The use of force and restraints of whatever nature should not be authorized unless strictly necessary for safeguarding the child’s or others’ physical or psychological integrity, in conformity with the law and in a reasonable and proportionate manner and with respect for the fundamental rights of the child (para. 97).

• Restraint by means of drugs and medication should be based on therapeutic needs and should never be employed without evaluation and prescription by a specialist (para. 97).

2. Persons placed in mental health facilities177

The MI Principles, CPT Standards and Council of Europe Rec(2004)10 all permit restraint and seclusion, but placing limits on their use. For example:

• Staff in psychiatric establishments “should receive training in both non-physical and manual control techniques vis-à-vis agitated or violent patients”. 178

• Individuals who are restrained or secluded “shall be kept under humane conditions and be under the care and close and regular supervision of qualified members of the staff”. 179

• Seclusion and restraint should never be used as a punishment. 180

• Seclusion or restraint should only be used “under medical supervision” and in “appropriate facilities, and in compliance with the principle of least restriction, to prevent imminent harm to the person concerned or others, and in proportion to the risks entailed”. 181

Standards relating to persons receiving mental health care also require that the use of restraint and seclusion be recorded. For example, the CPT Standards state that a specific register should be established to record all uses of means of restraint. The record should include the times at which the measures began and ended, the circumstances of the case, the reasons for its use, the name of the doctor authorizing it and any injuries sustained by patients or staff (para. 52). 182

J. COMPLAINTS AND INVESTIGATIONS

The importance of establishing effective complaints procedures and mechanisms to investigate allegations of human rights abuses is highlighted in both international and European human rights instruments.183 For example, under the ECHR, an independent investigation, capable of leading to the identification and punishment of those responsible, must take place when a person has died in circumstances which might amount to a breach of article 2 of the Convention (the right to life). 184
1. Children in alternative care

The Committee on the Rights of the Child has urged States to establish “an accessible, child-sensitive complaint mechanism” as part of the work to prevent abuse of and violence against children with disabilities.185

The independent expert for the United Nations study on violence against children highlighted the importance of establishing an effective complaints mechanism for children and ensuring the effective monitoring of and regular access to care and justice institutions by independent bodies empowered to conduct unannounced visits.186 The Guidelines for Alternative Care also recommend in paragraph 99 that:

- “Children in care should have access to a known, effective and impartial mechanism whereby they can notify complaints or concerns regarding their treatment or conditions of placement.”

- Young people should be involved in this process, “due weight being given to their opinions”.

- The process “should be conducted by competent persons trained to work with children and young people”.

2. Persons with disabilities

The Special Rapporteur on torture has highlighted the need for States to take specific action to address the “continued reports of indignities, neglect, violence and abuse perpetrated against persons with disabilities”. He recommends that States make available accessible complaints procedures and that relevant United Nations and regional human rights mechanisms, including those addressing individual complaints and conducting monitoring of places of detention, take full account of the new standards contained in the CRPD in their work.187

Article 33 of the CRPD requires States parties to establish a range of mechanisms to “promote, protect and monitor” the implementation of the CRPD. Establishing a system to examine individual complaints will be an important aspect of this work.188

3. Persons placed in mental health facilities

The right to make a complaint is set out in principle 21 of the MI Principles, but leaves the detail to be decided at the national level: “Every patient and former patient shall have the right to make a complaint through procedures as specified by domestic law.” However, States must ensure that “appropriate mechanisms” are in force “for the submission, investigation and resolution of complaints and for the institution of appropriate disciplinary or judicial proceedings for professional misconduct or violation of the rights of a patient” (principle 22).

Although the right to make a complaint is not made explicit in Rec(2004)10, article 37, entitled “Specific requirements for monitoring”, identifies “ensuring that complaints procedures are provided and complaints responded to appropriately” as one of the specific areas to be included when monitoring compliance with the rights set out in the standards. Ensuring that there are powers to “investigate the death of persons subject to involuntary placement or involuntary treatment, and that any such death is notified to the appropriate authority and is subject to an investigation” is also listed as a monitoring requirement.

K. AFTERCARE

The provision of support to enable individuals receiving formal care to return to their home environment is underpinned by rights such as the right to health189 and the right to social security.190 For example, article 26 of the CRPD requires States parties to “organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services” in order to enable persons with disabilities to “attain and maintain maximum independence” and “full inclusion and participation in all aspects of life”.
The European Social Charter (revised) includes a range of provisions relevant to the provision of aftercare for children and persons with disabilities. For example, article 23 (The right of elderly persons to protection) provides for health care and housing to enable the elderly to lead independent lives. ¹⁹¹

1. **Children in alternative care**

Article 23 of the CRC stipulates that States parties recognize the right of children with disabilities to receive special care and assistance subject to available resources and free of charge wherever possible. Such care and assistance “shall be designed to ensure that children with disabilities have effective access to and benefit from education, training, health care services, recovery services, preparation for employment and recreation opportunities”. ¹⁹² In relation to children in institutions, the Committee urges States to establish programmes for deinstitutionalization, re-placing children with their families, extended families or foster care system. In addition, parents and other extended family members “should be provided with the necessary and systematic support/training for including their child back into their home environment”. ¹⁹³

The Guidelines for Alternative Care include a range of recommendations in relation to aftercare in paragraphs 131-136. These emphasize the importance of starting the planning for aftercare as soon as possible and “in any case, well before the child leaves the care setting”, and that the “transition from care to aftercare takes into account the child’s gender, age, maturity and particular circumstances”; it should provide support to avoid exploitation and help the child to prepare for independent life and be able to integrate fully in the community. Importantly, children should be encouraged to take part in the planning of their aftercare.

2. **Persons placed in mental health facilities**

The standards for mental health care provide minimal guidance on preparing for discharge and aftercare. This is another area in which the standards relating to prisoners provide far more detailed guidance, in particular emphasizing the importance of preparing for release as soon as possible. For example, the European Prison Rules state that the regime for sentenced prisoners will start as soon as the person has been admitted to prison with the status of a sentenced prisoner and that “as soon as possible after such admission, reports shall be drawn up for sentenced prisoners about their personal situations, the proposed sentence plans for each of them and the strategy for preparation for their release” (rule 103.2). ¹⁹⁴

Principle 7 of the MI Principles states that where treatment takes place in a mental health facility, the person has the right to “return to the community as soon as possible”, and principle 8 states that all patients have the right to “such health and social care as is appropriate to his or her health needs, and is entitled to care and treatment in accordance with the same standards as other ill persons”. Council of Europe Rec(2004)10 highlights the importance of aftercare; article 24 (4) states that member States “should aim to minimise, wherever possible, the duration of involuntary placement by the provision of appropriate aftercare services”.

The Explanatory Notes to article 24 comment on the need for member States to take measures “to make alternatives to involuntary placement and to involuntary treatment as widely available as possible”, emphasizing that if appropriate services are available in the community the length of stay in hospital can be reduced: “After-care provision that links hospital and community services, and which is able to provide more intensive support immediately after the discharge of a patient from hospital may allow the patient to be discharged from involuntary placement earlier than would otherwise be the case” (para. 175). ¹⁹⁵ In some cases the availability of such services will obviate the need for admission in the first place.
VII. Developing alternatives to institutionalization

A. OVERVIEW

This chapter considers the duty of States to take action to develop community-based alternatives to institutional care, thus enabling people to exercise their right to community living.

By way of example, this obligation is made clear in relation to persons with disabilities in article 19 of the CRPD, which provides that persons with disabilities have the right to live and participate in the community with choices equal to others. It also requires States parties to “take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community”.

This means that a range of community-based services must be available. Such services must not only “support living and inclusion in the community”, but also “prevent isolation or segregation from the community” (art. 19 (b)). In addition, article 19 (c) requires that mainstream community services and facilities be “available on an equal basis to persons with disabilities and... responsive to their needs”.

B. THE DEVELOPMENT OF THE RIGHT TO COMMUNITY LIVING

While the CRPD is focused on persons with disabilities, the right to live and participate in the community is the right of each and every human being. Furthermore, although the CRPD is the first United Nations human rights treaty to give explicit recognition to the right to community living, the right has been acknowledged by United Nations treaty bodies for a number of years. For example:

• “[N]ational policies should help elderly persons to continue to live in their own homes as long as possible, through the restoration, development and improvement of homes and their adaptation to the ability of those persons to gain access to and use them.”

• “States parties are encouraged to invest in and support forms of alternative care that can ensure security, continuity of care and affection, and the opportunity for young children to form long-term attachments based on mutual trust and respect, for example through fostering, adoption and support for members of extended families.”

The Council of Europe has also emphasized the importance of enabling people to live and participate in the community. For example, the European Social Charter (revised) includes rights which seek to promote community living for children, persons with disabilities and older persons:

• Article 15 (The right of persons with disabilities to independence, social integration and participation in the life of the community) requires the parties to promote for persons with disabilities their “full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure”.

• Articles 16 (The right of the family to social, legal and economic protection) and 17 (The right of children and young people to social, legal and economic protection) highlight the importance of promoting family life and requires the parties, “with a view to ensuring the effective exercise” of their right to grow up in an “environment which encourages the full development of their personality and of their physical and mental capacities”, to ensure that children have the care, assistance and training they need.
• Article 23 (The right of elderly persons to social protection) requires the parties, “with a view to ensuring the effective exercise of the right of elderly persons to social protection”, to adopt or encourage various measures, in particular “to enable elderly persons to choose their life-style freely and to lead independent lives in familiar surroundings for as long as they wish and are able by means of the provision of housing suited to their needs and state of health or of adequate support for adapted housing (and) the health care and services necessitated by their state”.

C. THE IMPORTANCE OF DEVELOPING ALTERNATIVES TO INSTITUTIONALIZATION

The importance of developing alternatives to institutionalization has been highlighted by human rights bodies within the United Nations and the Council of Europe. For example, as noted above, the Committee on the Rights of the Child has urged States to “set up programmes for de-institutionalization of children with disabilities, re-placing them with their families, extended families or foster care system”. 199

Similarly, the Guidelines for Alternative Care highlight the need to eliminate institutional care: “While recognizing that residential care facilities and family-based care complement each other in meeting the needs of children, where large residential care facilities (institutions) remain, alternatives should be developed in the context of an overall deinstitutionalization strategy, with precise goals and objectives, which will allow for their progressive elimination” (para. 23).

As discussed in chapter I, the Guidelines for Alternative Care emphasize that the removal of children from their families “should be seen as a measure of last resort” and for the shortest possible time. They stress that, in the light of expert opinion, alternative care for young children, especially those under 3 years “should be provided in family-based settings”. Exceptions to this principle are limited to preventing siblings from being separated, dealing with emergency cases, or where the placement is “for a predetermined and very limited duration, with planned family reintegration or other appropriate long-term care solution as its outcome” (para. 22).

The Parliamentary Assembly of the Council of Europe has also stressed the need for Governments to take action to address the institutionalization of adults and children with disabilities, as those placed in such institutions are “kept segregated from the rest of society and suffer serious damage to their healthy development and obstruction of the exercise of other rights”. Crucially, “deinstitutionalisation is a prerequisite to enabling persons with disabilities to become as independent as possible and take their place as full citizens with the opportunity to access education and employment, and a whole range of other services.” 200

CM/Rec(2010)2 also emphasizes the need for Governments to take a strategic approach to the development of community-based services as alternatives to institutions. “Deinstitutionalisation being a long-term process”, it is suggested that Governments will need to develop national strategies to manage the transition from institutional care to community-based services. In relation to the creation of community-based services, the recommendation states: “A national action plan and a timetable should be drawn up to phase out institutional placements and replace these forms of care with a comprehensive network of community provision. Community-based services should be developed and integrated with other elements of comprehensive programmes to allow children with disabilities to live in the community” (para. 20).

Thus, an essential factor in achieving the social inclusion of children, persons with disabilities and older persons currently living in institutions is to facilitate the closure of institutions, through focused strategies that ensure the development of community-based alternatives. The need for such concerted work was stressed by the Ad Hoc Expert Group on the Transition from Institutional to Community-based care. In its report the Expert Group recommended that EU member States should “adopt strategies and action plans... accompanied by a clear timeframe and budget for the development of services in the community and the closure of long-stay institutions”, with a “proper set of indicators to measure the implementation of these action plans.” 201
However, transferring from institutional care to community-based services is not, in itself, sufficient to ensure that children, persons with disabilities and older persons can exercise their right to live and participate in the community. For example, OHCHR considers that in order to achieve the objectives of article 19 of the CRPD, Governments will in most cases need to develop national strategies that cover the areas of social services, health, housing and employment. In addition, for the effective implementation of such strategies, legislation must establish independent living as a legal right, place duties on authorities and service providers and also allow for recourse in case of violation. As noted in the OHCHR Thematic Study on the Convention:

Such legislative frameworks shall include the recognition of the right to access the support services required to enable independent living and inclusion in community life, and the guarantee that independent living support should be provided and arranged on the basis of the individual’s own choices and aspirations, in line with the principles of the Convention.202
VIII. Conclusion

This report has emphasized that, under international and European human rights law, Governments should transfer from a system of institutional care to alternative community-based services that enable children, persons with disabilities (including users of mental health services) and older people to live and participate in the community. It has also sought to highlight the importance of developing standards to monitor the situation of children, persons with disabilities and older persons living in all formal care settings. This is because during the transition from institutional care to community-based services, Governments will need to protect the rights of children, persons with disabilities and older persons who currently reside in institutions. They will also need to ensure compliance with human rights standards when monitoring the situation of persons receiving community-based residential services.

However, this report’s analysis of United Nations and Council of Europe human rights instruments shows that the standards specific to the care and treatment of children, persons with disabilities and older persons in formal care settings are neither comprehensive nor, in some areas, compatible with current human rights law. In comparison to prisoners and others deprived of their liberty, there are few standards that specifically address the human rights of individuals living in formal care settings. Although guidance has been developed in relation to persons receiving mental health care and children deprived of parental care, too little attention has been given to the need to develop clear standards for the care and treatment of persons living in formal care settings. In particular, there are very few standards specific to older people.

Furthermore, serious doubts have been raised about the compatibility of the United Nations Principles for the protection of persons with mental illness and the improvement of mental health care and Council of Europe Recommendation Rec(2004)10 with the CRPD. Both relate to the care and treatment of persons receiving mental health care. They will require substantial revision, especially those provisions concerning consent to treatment, legal capacity and deprivation of liberty. (As discussed in the introduction to this report, to the extent that provisions of the MI Principles and Rec(2004)10 conflict with the CRPD, they should be deemed obsolete.) Another serious concern is the lack of attention given to enabling those in formal care settings to exercise their human rights, such as the right to private and family life and the right to engage in political and public life.

As noted throughout this report, the CRPD has the potential to significantly influence the development of standards relating to the care and treatment of children and older persons in formal care settings, as well as persons with disabilities. This is because the CRPD makes clear that persons with disabilities have equal rights to others. It “identifies areas where adaptations have to be made so that persons with disabilities can exercise their rights and areas where the protection of their rights must be reinforced because those rights have been routinely violated”. Given this strong and positive approach to individuals’ rights, the CRPD will provide an important guide in developing standards that reflect the need to protect and promote the human rights and dignity of all persons in formal care settings.

Such standards must not only seek to ensure good quality of care; they must also aim to enhance the quality of life of individuals using such services and enable them to achieve their aspirations and engage in community life. In addition, the CRPD makes clear that the development and implementation of these quality monitoring systems should involve the individuals receiving these services (including children) and their representative organizations.

In essence, the CRPD shows how and why States parties must, as a matter of priority, take effective and appropriate measures to facilitate the full inclusion and participation of children, persons with disabilities and older persons in the community.
Annex

United Nations and Council of Europe Human Rights Standards

Set out below is a non-exhaustive list of international and European standards and recommendations relevant to the situation of persons in institutions.

I. UNITED NATION STANDARDS AND PRINCIPLES

Core human rights treaties

1. International Covenant on Economic, Social and Cultural Rights, 1966
2. International Covenant on Civil and Political Rights, 1966
   - Optional Protocol to the International Covenant on Civil and Political Rights, 1966
   - Second Optional Protocol to the International Covenant on Civil and Political Rights, 1989
   - Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women, 1999
5. Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 1984
   - Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, 2002

General comments of the committees established under the core international human rights treaties

Committee on Economic, Social and Cultural Rights
- General comment No. 3 (1990) on the nature of States parties’ obligations
- General comment No. 5 (1994) on persons with disabilities
- General comment No. 6 (1995) on the economic, social and cultural rights of older persons
- General comment No. 14 (2000) on the right to the highest attainable standard of health
- General comment No. 20 (2009) on non-discrimination in economic, social and cultural rights
Human Rights Committee
- General comment No. 8 (1982) on article 9 of the International Covenant on Civil and Political Rights (Right to liberty and security of persons)
- General comment No. 16 (1988) on article 17 (Right to privacy)
- General comment No. 17 (1989) on article 24 (Rights of the child)
- General comment No. 18 (1989) on non-discrimination
- General comment No 20 (1992) on article 7 (Prohibition of torture or other cruel, inhuman or degrading treatment or punishment)

Committee on the Rights of the Child
- General comment No. 7 (2006) on implementing child rights in early childhood
- General comment No. 9 (2006) on the rights of children with disabilities
- General comment No. 12 (2009) on the right of the child to be heard

Committee on the Elimination of Discrimination against Women
- General recommendation No. 18 (1991) on disabled women
- General recommendation No. 27 (2010) on older women and protection of their rights

Non-binding human rights standards

Rights of the child
- Guidelines for the Alternative Care of Children, 2009

Rights of persons with disabilities
- Declaration on the Rights of Disabled Persons, 1975
- Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993

Rights of persons with mental health problems
- Principles for the protection of persons with mental illness and the improvement of mental health care, 1991
- Commission on Human Rights resolution 2005/24 on the right of everyone to the highest attainable standard of physical and mental health

Rights of older persons
- United Nations Principles for Older Persons, 1991
- Political Declaration and Madrid International Plan of Action on Ageing, 2002

Rights specifically connected with deprivation of liberty
- Standard Minimum Rules for the Treatment of Prisoners, 1955
- Declaration on the Protection of All Persons from Being Subjected to Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 1975
- Principles of Medical Ethics relevant to the Role of Health Personnel, particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 1982
- Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment, 1988
- Basic Principles for the Treatment of Prisoners, 1990

**United Nations reports**

Reports of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health:

- Report of the Special Rapporteur to the Commission on Human Rights at its sixty-first session (E/CN.4/2005/51)

Reports of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment:

- Interim report of the Special Rapporteur to the General Assembly at its sixty-third session (2008) (A/63/175)
- Report of the Special Rapporteur to the Human Rights Council at its thirteenth session ((2010): addendum: Study on the phenomena of torture, cruel, inhuman or degrading treatment or punishment in the world, including an assessment of conditions of detention (A/HRC/13/39/Add.5)


United Nations study on violence against children

- Reports of the independent expert for the United Nations study on violence against children (A/61/299 and A/62/209)

**II. COUNCIL OF EUROPE STANDARDS, GUIDELINES AND RECOMMENDATIONS**

**Core human rights treaties**

2. European Social Charter, 1961
3. European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, 1987
4. European Social Charter (revised), 1996

**European Court of Human Rights case law**

_Ashingdane v. The United Kingdom_, application No. 8225/78, 1985  
_Assenov and Others v. Bulgaria_, application No. 24760/94, 1998  
_Herczegfalvy v. Austria_, application No. 10533/83, 1992  
_H.L. v. The United Kingdom_, application No. 45508/99, 2005 (see para. 89)  
_Kutzner v. Germany_, application No. 46544/99, 2002 (see para. 81)  
_Megyeri v. Germany_, application No. 13770/88, 1992  
_Pretty v. The United Kingdom_, application No. 2346/02, 2002  
_Price v. The United Kingdom_, application No. 33394/96, 2001  
_Shtukaturov v. Russia_, application No. 44009/05, 2008,  
_Winterwerp v. The Netherlands_, application No. 6301/73, 1981  
_Witold Litwa v. Poland_, application No. 26629/95, 2000 (see para. 78)  
_X. v. The United Kingdom_, application No. 7215/75, 1982  
_Z. v. Finland_, application No. 22009/93, 1997

**Non-binding human rights standards**

**Rights of the child**
- Recommendation Rec(2005)5 of the Committee of Ministers to member states on the rights of children living in residential institutions
- Recommendation CM/Rec(2010)2 of the Committee of Ministers to member states on deinstitutionalisation and community living of children with disabilities
- Parliamentary Assembly of the Council of Europe Recommendation 1934 (2010) on child abuse in institutions: ensuring full protection of the victims

**Rights of persons with disabilities**
- Council of Europe Action Plan to promote the rights and full participation of persons with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015 (Committee of Ministers Recommendation Rec(2006)5)

**Rights of persons with mental health problems**
- Council of Europe Guidelines concerning the protection of the human rights and dignity of persons with mental disorder (Council of Ministers Recommendation Rec(2004)10)
- European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), CPT standards, CPT/Inf/E (2002) 1-Rev. 2010
Rights of older people

- Recommendation CM/Rec(2009)6 of the Committee of Ministers to member States on ageing and disability in the 21st century: sustainable frameworks to enable greater quality of life in an inclusive society

Rights of persons deprived of their liberty

- CPT standards (see above under Rights of persons with mental health problems)
- Recommendation Rec(2006)2 of the Committee of Ministers to member states on the European Prison Rules
- Recommendation CM/Rec(2008)11 of the Committee of Ministers to member states on the European Rules for juvenile offenders subject to sanctions or measures

Reports

- Recommendations and Guidelines to promote community living for children with disabilities and deinstitutionalization, as well as to help families to take care of their disabled child at home, adopted by the Council of Europe Committee on the Rehabilitation and Integration of People with Disabilities (Partial Agreement) (CD-P-RR) on 31 December 2007

III. EU DOCUMENTS

Human rights standards

- Charter of Fundamental Freedoms of the European Union

Reports

Article 1 of the Convention on the Rights of the Child (CRC) defines a child as “every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier”.  

Article 1 of the Convention on the Rights of Persons with Disabilities (CRPD) states: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”  

The Committee on Economic, Social and Cultural Rights (CESCR) notes, in its general comment No. 6 (1995) on the economic, social and cultural rights of older persons, that the terminology to describe older persons varies considerably. The Committee opted for “older persons” and uses this term to cover persons aged 60 and above (para. 9).  

The Guidelines for the Alternative Care for Children therefor “Guidelines for Alternative Care”, annexed to General Assembly resolution 61/142 of 18 December 2009, defines formal care as “all care provided in a family environment which has been ordered by a competent administrative body or judicial authority, and all care provided in a residential environment, including in private facilities, whether or not as a result of administrative or judicial measures” (para. 29 (a) (iii)).  


See for example the report of the United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health [hereafter “Special Rapporteur on the right to health”] (E/CN.4/2005/51).  

For example, the Council of Europe Commissioner for Human Rights, Thomas Hammarberg, recently commented on the inhuman treatment of persons with disabilities in institutions, highlighting concerns about the “substandard conditions” and the “object neglect and severe human rights abuses” suffered by residents, and that in “too many cases, premature deaths are not investigated or even reported”. See “Inhuman treatment of persons with disabilities in institutions”, posted on 21 October 2010 at http://commissioneer.cws.Council of Europe.int/tiki-view_blog.php?blogId=1&bl=xy. See also Mental Disability Advocacy Center, Cage Beds, Inhuman and Degrading Treatment in Four Accession Countries (Budapest, 2003); Bulgarian Helsinki Committee, The Archipelago of the Forgotten: Social Care Homes for People with Mental Disorders in Bulgaria, 2005 and Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care, European Commission, Directorate-General for Employment, Social Affairs and Equal Opportunities, 2009.  


CRC/C/HUN/CO/2, para. 30.  

Recommendations and Guidelines to promote community living for children with disabilities and deinstitutionalisation, as well as to help families to take care of their disabled child at home, adopted by the Council of Europe Committee on the Rehabilitation and Integration of People with Disabilities (Partial Agreement) (CD-P-RR) on 31 December 2007.  

See annex.  

See www2.ohchr.org/english/law/.  


See: www.Council of Europe.int/aboutCouncil of Europe/.  


See Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, art. 4 [2] and rule 11 [b] of the United Nations Rules for the Protection of Juveniles Deprived of their Liberty.  

See for example the Standard Rules for the Equalization of Opportunities of Persons with Disabilities and the report of the Special Rapporteur on the right to health (A/HRC/7/11), paras. 42 and 43.  

United Nations human rights treaties give specific recognition to the need to protect children and persons with disabilities from discrimination. For example, the CRPD identifies women with disabilities as being vulnerable to multiple discrimination and therefore requiring special protection (art. 6). See also the Committee on the Elimination of Discrimination against Women (CEDAW), general recommendations No. 18 (1991) on disabled women and No 27 on older women and protection of their rights. Article 7 of the CRPD requires States to take measures to ensure that children with disabilities enjoy all human rights and fundamental freedoms on an equal basis with other children. Article 2 of the Convention on the Rights of the Child requires States to respect and ensure all the rights set forth in the Convention to all children without discrimination.  

General comment No. 20 (2009) on non-discrimination in economic, social and cultural rights, para. 7.  

See International Convention on the Elimination of All Forms of Racial Discrimination, art. 1; Convention on the Elimination of All Forms of Discrimination against Women, art. 1; and CRPD, art. 2. The CESCR notes that the Human Rights Committee has adopted a similar interpretation in its general comment No. 18 (1989) on non-discrimination, paras. 6 and 7.  

General comment No. 20 (2009) on non-discrimination in economic, social and cultural rights, para. 7.
29 Ibid., para. 9.
30 See also Thematic Study on the CRPD.
32 See also Rec(2005)5 and the Council of Europe Action Plan to promote the rights and full participation of persons with disabilities in society: improving the quality of life of persons with disabilities in Europe 2006-2015, which highlights the need to support ageing persons with disabilities to remain in their communities.
33 General comment No. 12 (2009) on the right of the child to be heard, para. 1. See also paragraph 20 in which the Committee considers the issue of the child’s capacity to make decisions for him- or herself.
34 Pretty v. The United Kingdom, application No. 2346/02, 2002, para. 61.
35 Recommendation CM/Rec(2009)16 points out that these are two distinct but related groups of people. The first group refers to people who grow old having experienced a disability for much of their lives, sometimes from birth. The second group refers to people whose first experience of disability is at a relatively advanced age.
36 See also article 14 of the Political Declaration and Madrid International Plan of Action on Ageing, 2002: “We shall promote independence, accessibility and the empowerment of older persons to participate fully in all aspects of society.”
37 Kutzner v. Germany, application No. 46544/99, para. 81. See also Rec(2004)10, art. 8 (Principle of least restriction).
38 For further information on the right to vote, see FRA - European Union Agency for Fundamental Rights, The right to political participation of persons with mental health problems and persons with intellectual disabilities, October 2010. Available at www.fra.europa.eu.
39 General comment No. 25 (1996) on participation in public affairs and the right to vote, para. 5.
41 See also general comment No. 12 (2009) and the recommendations on participation in the report of the independent expert for the United Nations study on violence against children (A/61/299), para. 103.
42 CM/Rec(2009)16, para. 2.2. See also article 5 of the Political Declaration and Madrid Plan of Action on Ageing, 2002.
43 See article 9 of the ICCPR, article 14 of the CRPD, article 37 of the CRC and article 5 of the ECHR.
44 See article 8 of the ECHR, article 17 of the ICCPR, article 16 of the CRC and article 22 of the CRPD.
45 See article 19 of the CRPD. This right is discussed in more detail in chapter VII.
46 Issues relating to the right to private and family life are considered in chapter VI and to the right to community living in chapter VII.
47 Witold Litwa v. Poland, application No. 26629/95, 2000, para. 78.
48 H.L. v. The United Kingdom, application No. 45508/99, para. 89.
50 Ashingdane v. The United Kingdom, application No. 8225/78, 1985.
52 Ibid., para. 15. Similar concerns about the inadequate protection provided by mental health law in some countries have been raised by the Human Rights Committee. See the Committee’s concluding observations on the Czech Republic (CCPR/C/CZE/ CO/2, 2007).
53 Shhtukaturov v. Russia, application No. 44009/05, 2008, para. 107.
54 In the light of the serious and complex issues concerning the implementation of article 12 of the CRPD, OHCHR will be undertaking further research in this area.
55 See Thematic study on the CRPD, paras. 43–47.
56 See Winterwerp v. The Netherlands, application No. 6301/73, 1981.
57 See MI Principles, Definitions.
58 See Thematic Study on the CRPD, paras. 48 and 49.
59 Ibid.
60 Article 37 (4) of the CRC and article 5 (4) of the ECHR.
61 See X v The United Kingdom, application No. 7215/75, 1982.
63 Megeri v. Germany, application No. 13770/88, 1992, para. 23.
64 Other examples include rule 7 of the United Nations Standard Minimum Rules for the Treatment of Prisoners and rule 20 of the United Nations Rules for the Protection of Juveniles Deprived of their Liberty.
65 See for example article 10 of the ICCPR, articles 37 and 40 of the CRC, rule 8 of the Standard Minimum Rules for the Treatment of Prisoners and rule 26 of the United Nations Standard Minimum Rules for the Administration of Juvenile Justice (The Beijing Rules).
66 See for example rule 15.1 of the European Prison Rules.
67 For example, see rules 21 and 23 of the United Nations Rules for the Protection of Juveniles Deprived of their Liberty.
68 See for example rule 24 of the Standard Minimum Rules for the Treatment of Prisoners, rule 42 of the European Prison Rules, rule 62 of the European Rules for juvenile offenders and the CPT Standards.
69 States that have ratified the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, 1987 have agreed to allow the CPT to visit places where persons are deprived of their liberty, e.g., prisons, psychiatric hospitals and social care homes, to assess how they are treated (see article 1).
71 See chap. II - Prisons, “Health care services in prisons”, pp. 27ff. The CPT also applies these standards to persons in psychiatric
71 See also Human Rights Committee general comment No. 8 (1982) on article 9 (Right to liberty and security of persons), para. 4.
72 There are extensive rules in the standards relating to prisoners on the provision of information. See for example rule 30 of the European Prison Rules, principle 14 of the Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment and rule 24 of the United Nations Rules for the Protection of Juveniles Deprived of their Liberty.
73 See also Rec(2004)10, art. 22.
74 CPT/Inf/E (2002) 1-Rev. 2010, para. 53. By way of comparison, rule 24 of the United Nations Rules for the Protection of Juveniles Deprived of their Liberty states that those who cannot understand the language in the written form should have the information conveyed to them in a manner that will enable their “full comprehension”.
75 See article 22 of Rec(2004)10 and principle 12 of the MI Principles.
76 Such proceedings will also need to take account of the views of the child in accordance with article 12 (Respect for the views of the child). See the statement by the Committee on the Rights of the Child that such proceedings should be accessible and child appropriate (general comment No. 12 (2009) on the right of the child to be heard, paras. 32–34).
77 General comment No. 9 (2006) on the rights of children with disabilities, para. 47.
78 General comment No. 7 (2006) on implementing child rights in early childhood, para. 36 (d).
79 A/64/272, para. 72.
80 Ibid., para. 48.
81 Ibid., para. 51.
82 A/63/175, para. 74.
83 See for example article 12 of the ICESCR and article 25 of the CRPD.
84 See for example article 8 of the ECHR.
85 See for example article 7 of the ICCPR and article 3 of the ECHR.
86 Pretty v. The United Kingdom, application No. 2346/02, 2002, para. 63.
88 Article 7 of the ICCPR prohibits medical or scientific experiments without the person’s “free consent”.
89 A/63/175, para. 47.
90 General comment No. 14 (2000) on the right to the highest attainable standard of health (art. 42), para. 34.
91 A/63/175, para. 44.
92 Article 12 (1) is quoted in chap. II.C.
93 General comment No. 12 (2009) on the right to be heard, para. 1.
94 Ibid., para. 20.
95 Ibid., para. 100. See also general comment No. 4 (2003) on adolescent health and development in the context of the Convention on the Rights of the Child.
98 Ibid., pp. 12 and 13.
99 See article 17 (Protecting the integrity of the person) of the CRPD.
100 See article 25 (Health) of the CRPD.
101 See A/64/272, paras. 69-74.
102 A/63/175, para. 63, referring to the Human Rights Committee’s decision in Viana Acosta v. Uruguay.
103 A/58/181, para. 45.
105 See articles 18 and 20.
106 See article 5 and article 7. See also article 6 (3) which concerns persons who lack capacity to consent due to a “mental disability” and article 26 (situations in which the rights under the Convention can be restricted).
107 CPT standards, para. 41.
108 A/64/272, para. 51.
109 Ibid., para. 53.
110 General recommendation No. 27 (2010) on older women and protection of their rights, paras. 21 and 45.
111 See for example article 2 (1) of the ICCPR and article 2 (2) of the ICESCR and CESCR general comment No. 3 (1990) on the nature of States parties’ obligations.
112 These include article 10 of the ICCPR and article 11 of the CAT.
113 General comment No. 20 (1992) on article 7 of the ICCPR (Prohibition of torture, or other cruel, inhuman or degrading treatment or punishment).
114 See paragraph 2 of the report of the Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment of Punishment on its visit to Mexico in 2008 [CAT/OP/MEX/1].
115 See also Rec(2005)5.
118 It also refers to the Council of Europe Convention on the Protection of Children against Sexual Exploitation and Sexual Abuse (CETS No. 201), which came into force in July 2010.
119 The World Health Organization is developing a toolkit to help Governments establish human rights monitoring mechanisms.
and holding of information” in general comment No. 16 (1988) on the right to privacy, para. 10.

See also general comment No. 20 [2009] on non-discrimination in economic, social and cultural rights, para. 29, which highlights that “age is a prohibited ground of discrimination in several contexts” (such as employment), and article 5 of the Political Declaration and Madrid International Plan of Action on Ageing, 2002, which also highlights the need to address abuse against older persons.

See also principle 13 of the United Nations Principles for Older Persons.


Principle 8 (1) of the MI Principles; see also the CPT Standards which state that prisoners “are entitled to the same level of medical care as persons living in the community at large”. The criteria that the CPT applies in relation to health care services for prisoners (access to a doctor; equivalence of care; patient’s consent and confidentiality; preventive health care; professional independence as persons living in the community at large”. The criteria that the CPT applies in relation to health care services for prisoners (access to a doctor; equivalence of care; patient’s consent and confidentiality; preventive health care; professional independence and quality.

See under the section headed “Guidelines and quality standards”.

Principle 7 (3) of the MI Principles.

Rec[2004]10, art. 4.

See principle 13 of the United Nations Principles for Older Persons.


See CM/Rec(2009)6, para. 1.4.

General comment No. 14 (2000) on the right to the highest attainable standard of health, para. 1. At paragraph 12, the Committee explains that the right to health contains four interrelated and essential elements: availability, accessibility, acceptability and quality.


CPT standards, para. 54 and principle 13 of the MI Principles.

CPT standards, para. 54.

Principle 9 (4) of the MI Principles.

CPT standards, para. 37.

Principle 9 (4) of the MI Principles.

Rec[2004]10, art. 10.

See general comment No. 6 (1995) on the economic, social and cultural rights of older persons, paras. 34 and 35.

See also article 11 of Rec(2004)10 and principle 14 of the MI Principles.

CM/Rec(2009)6, para. 1.16.

See also comments by the Human Rights Committee on the “gathering and holding of information” in general comment No. 16 [1988] on the right to privacy, para. 10.
165 See United Nations Basic Principles for the Treatment of Prisoners, principle 8.
166 European Prison Rules, rule 26.
167 Standard Minimum Rules for the Treatment of Prisoners, rule 71; see also European Prison Rules, para. 26.5.
168 See also rules 42–46 of the Rules on Juveniles and the Recommendation of the Committee of Ministers to member states on the European Rules for juvenile offenders subject to sanctions or measures (CM/Rec(2008)11) which also cover vocational training and employment.
169 See concluding observations of the Committee on the Rights of the Child: Bulgaria (CRC/C/BGR/CO/2, 2008), para. 40 (e).
170 See also Rec(2005)5.
171 See also rules 42–46 of the United Nations Rules for the Protection of Juveniles Deprived of their Liberty (covering vocational training and employment).
172 A/63/175, para. 55.
173 ICCPR/CO/78/SVK, para. 13 and ICCPR/C/CZE/CO/2, para. 13.
174 A/63/175, para. 56.
176 See also Rec(2005)5.
178 CPT standards, para. 47.
179 Principles for the protection of persons with mental illness and the improvement of mental health care, principle I (I).
180 CPT standards, para. 49; see also Rec(2004)10, art. 27.
181 Rec(2004)10, art. 27. Although this article does not apply to “momentary restraint”, the Explanatory Notes state that this expression should be interpreted strictly and that the concept “is intended to cover only very brief gentle physical holding of a person, for example by placing a hand on the person’s arm” (para. 192).
182 See also principle I (11) of the MI Principles and article 27 of Rec(2004)10.
183 The right to an effective remedy for any violation of rights and freedoms is a core principle of human rights treaties, such as the ICCPR (art. 2) and the ECHR (art. 13). See also the Human Rights Committee’s general comments No. 16 (1988) on article 17 (right to privacy) and No. 31 (2004) on the nature of the general legal obligation imposed on States parties to the Covenant. Article 12 of CAT requires that States parties ensure a prompt and impartial investigation wherever there is “reasonable ground to believe that an act of torture has been committed”.
186 A/61/299, para. 112 (f).
187 A/63/175, paras. 73 and 74.
189 See article 12 of the ICESCR, article 24 of the CRC, article 25 of the CRPD and article 11 of the European Social Charter.
190 See article 9 of the ICESCR, article 26 of the CRC, article 28 of the CRPD and article 12 of the European Social Charter; see also article 15 of the European Social Charter (revised).
191 These provisions are discussed in detail in chapter VII below.
193 Ibid., para. 49.
194 See also rule 80 of the Standard Minimum Rules for the Treatment of Prisoners and rule 79 of the European Rules for juvenile offenders.
195 Similar points were made by the Human Rights Committee in its concluding observations on Canada (CCPR/C/CAN/CO/5, 2005), para. 17.
196 See also the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) and Commission on Human Rights resolution 2005/24, para. 7, in which the Commission called upon States “to introduce, as far as possible, community-based care and support for persons with disabilities related to mental disorders, in order to ensure their access to medical and social services that promote their independence and autonomy and support their social integration”.
197 CESC general comment No. 6 (1995) on the economic, social and cultural rights of older persons, para. 33, citing recommendation 19 of the Vienna International Plan of Action on Ageing adopted at the 1982 World Assembly on Ageing; see also Human Rights Committee, general comment No. 10 (1999) on article 24 (Rights of the child).
198 Committee on the Rights of the Child general comment No. 7 (2006) on implementing the rights of the child in early childhood, para. 36 (b).
200 Parliamentary Assembly of the Council of Europe, Report on access to rights for persons with disabilities and their full and active participation in society, doc. 11694, 8 August 2008, para. 44. See also CM/Rec(2010)2 of the Committee of Ministers to member States on deinstitutionalization and community living of children with disabilities.
202 A/HRC/10/48, para. 51.
204 See article 4 (3) of the CRPD. See also the discussion on participation in policy development in chapter II above.