

Section 8 **Guide to the prompt questions listed in Section 9 (30 Parts)**

This Section explains in detail the relationship between specific human rights contained in the CRPD and the type of real life situations you can expect during a monitoring visit to a mental health or social care institution. The structure follows the same thematic categories as those set out in the prompt questions for the visit in Section 9. While information needs to be gathered for each Part if that Part is applicable to the place being monitored, not all the questions need to be asked. They are provided to give prompts as to the sorts of issues the monitors may like to explore.

Parts 1 and 2 **Institution details**

This gathers institutional details – background information, statistical details and a general picture about the operation of the institution. Its location, accessibility and distance to the community are indicators of the institution's ability to foster community integration. Some institutions have gates and resemble prisons, while some are open. This information becomes meaningful when gathered in conjunction with the location of the institution, the rules about residents leaving and the regulations for receiving visitors.

Part 3 **Living standards and conditions**

The Part on living standards includes a number of elements, all of which impact on the human rights of people inside mental health or social care institutions. This Part seeks to find information, for example, on whether the institution has adequate electricity. Heating is an important issue in some countries, and without adequate heating the conditions can be such that the cold constitutes inhuman and degrading treatment or punishment. The final topic in this Part is hygiene, which is related to the right to health, the right to respect for home, and the right to integrity. This includes consideration of the general sanitary conditions: are the rooms clean, is the kitchen clean, are the toilets hygienic, are there adequate and clean facilities for people to wash? You may like to read CRPD Articles 15, 17, 19, 25, 28.

Part 4 **Involuntary commitment and review procedures**

People in institutions may be legally detained there under domestic law. Detention is a serious interference with human rights, and in the aftermath of the Second World War, the drafters of human rights treaties were anxious to prevent atrocities occurring in detention. People in institutions could be detained there through the law, such as a mental health law. Or they could be detained there by so-called de facto detention. This simply means that they are legally free to leave but the doors are locked so they cannot leave, or that the institution is so far away from their home or a town that it may be materially and physically impossible for them to go elsewhere. The Toolkit takes a descriptive approach to detention, because we know that detention of people with disabilities is a feature in the majority of countries. This Part asks a set of questions about the procedure for detention, and the availability of a court hearing to test the lawfulness of detention. Such a procedure would need to include notification to the detainee, provision of information to the detainee (including access to medical records) to give the detainee information upon which to build a case, access to a legal representative paid for by the State, and appeal processes. You may like to read CRPD Article 14.

Part 5 **Living independently and being included in the community after discharge**

Living in the community is one of the most important rights under the CRPD. Article 19 of the Convention says that every person with a disability has the right to live in the community 'with choices equal to others,' and that States are obliged to 'take effective measures to facilitate the full enjoyment [...] of this right.' The right to live in the community – on paper at least – puts a long-awaited end to life-long institutionalisation and segregation. A crucial element of the right to live in the community is the right for people with disabilities 'to choose their place of residence and where and with whom they live on an equal basis with others, and are not obliged to live in a particular living arrangement.' (Article 19(a)). The Toolkit has been developed because the reality is that people continue to be detained in institutions, and until this situation changes we need to make efforts to end the violations they experience in facilities and to promote their rights.

Part 6 **Participation in cultural life, recreation, leisure and sport**

Part of institutional life may mean that a detainee is not able to access cultural and leisure activities to which people in the community have access. Article 30 of the CRPD makes it clear that people with disabilities have the right ‘to take part on an equal basis with others in cultural life,’ and places an obligation on States to take all appropriate measures to ensure that people can enjoy access to such places such as theatres, cinemas, and libraries.

Part 7 **Participation in political and public life**

This Part addresses the availability within an institution for residents to participate in political and public life. What this means in CRPD terms is whether residents have access to exercise their right to vote. Article 29 of the CRPD states clearly that people with disabilities have the ‘right to vote and be elected’ (Article 29(a)). This Part therefore suggests that you ask whether people have access to polling stations, and attempts to tease out whether anyone is excluded from voting. Participation in public life also means that States have an obligation to encourage people with disabilities to join, form and participate in non-governmental organisations and associations concerned with the public and political life of the country, and participate in activities of political parties (Article 29(b)).

These provisions link with the new disability policies brought in by the Convention, in particular in Article 4(3) that ‘in the development and implementation of legislation and policies to implement [the CRPD] and in any other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations.’ It also links with the provision in Article 33(3) that persons with disabilities should be included in domestic mechanisms which monitor the implementation of the Convention.

Part 8 **Education, training, work and employment**

The CRPD confirms that part of being included in the community in terms of access to education and in having equal opportunities means that people with disabilities have the ‘right to work, on an equal basis with others’ (Article 27(1)). The CRPD makes unlawful all forms of discrimination in every aspect of employment: conditions of recruitment, continuance of employment, promotions and working conditions. Crucially, the CRPD also states that ‘reasonable accommodation’ must be provided to enable people with disabilities to enjoy the right to work (Article 27(1)). The CRPD defines

reasonable accommodation as the ‘necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms’ (Article 2). This Part therefore asks whether residents are or have the opportunity to have appropriate access to education, and to be employed in the institution and outside the institution.

Part 9 **Freedom of religion**

Freedom from State interference in choosing and practising one’s faith is a right enshrined in several human rights treaties such as Article 18(1) of the International Covenant on Civil and Political Rights. This provides the ‘right to freedom of thought, conscience and religion. This right shall include freedom to have or to adopt a religion or belief of his choice, and freedom, either individually or in community with others and in public or private, to manifest his religion or belief in worship, observance, practice and teaching.’ Persons with disabilities who suffer multiple forms of discrimination (including religious discrimination) are referred to in the perambulatory paragraph (p) of the CRPD.

Part 10 **Correspondence and visitors**

In an institution, the right to communicate with the outside world is sometimes curtailed. In human rights terms this is called the right to correspondence. This covers issues such as censorship of outgoing and incoming letters, and includes telephone calls and emails. Human rights law is quite clear that there are very few exceptions to the right to freely correspond with the outside world. The only exception might be when a third party is at risk. Letters to and from lawyers and courts (and other complaints mechanisms) enjoy a special status of never being subject to censorship. The CRPD deals with the right to correspondence by stating that ‘no person with disabilities, regardless of place of residence or living arrangement, shall be subjected to arbitrary or unlawful interference with his or her [...] correspondence or other type of communication [...]’ (Article 22(1)). The right to have visitors is important, especially when considering that the therapeutic goal of any mental health service is to enable the individual to rejoin the community.

Part 11 **Family and privacy rights: contraception, pregnancy and parenting, abortion, sterilisation**

Throughout history, people with disabilities have suffered from invasions of their privacy, including their bodily integrity. This has been widely documented. It is with vigour that the CRPD therefore protects against such abuses. Article 23 sets out a number of important family law rights. Firstly, States should prohibit discrimination of people with disabilities in areas related to marriage, family, parenthood and relationships (Article 23(1)), including choosing the number and spacing of children (Article 23(1)(b)), the right to retain fertility (Article 23(1)(c)) and to bring up children (Article 23(4)). This Part therefore addresses sensitive issues of contraception, pregnancy and parenting, and abortion and sterilisation. In doing so, it focuses on the consent of the person with disabilities, and on information and support provided to her or him to be able to make autonomous choices. It is to be noted that sterilisation is never a treatment for mental health problems or an intellectual disability, and having a diagnosis should not be a reason for sterilisation, or abortion.

Part 12 **Freedom of expression and opinion, and access to information**

Article 21 of the CRPD provides for the right to receive and impart information on an equal basis with others. This Part focuses on the right to information in relation to various aspects of life in institutions, and emphasises the importance of access to information for residents.

Part 13 **Freedom from torture, ill-treatment, abuse and neglect**

Abuse and neglect can happen in any institution, simply because of the nature of power and control of such places. Ill-treatment may happen because of an institutional culture of violence where neglect and abuse is allowed to continue with impunity. The CRPD addresses freedom from cruel, inhuman or degrading treatment or punishment in Article 15, and freedom from exploitation, violence and abuse in Article 16. An effective complaints system can contribute to preventing abuse. Such systems should be accessible to everyone to make a complaint, all complaints should be investigated, and remedies provided if the complaint is founded. Article 16(3) of the CRPD speaks of the importance of monitoring services provided to people with disabilities, and this connects with the requirement under the Optional Protocol to the UN Convention against Torture (see Section 2).

Part 14 **Restraint and seclusion**

Most mental health and social care institutions have policies – written or unwritten – about how they deal with challenging behaviours. Sometimes, institutions use manual restraint (person-to-person), sometimes physical restraints (straightjackets, towels tied to chairs, leather straps, cages), and sometimes chemical restraints (usually injected into the body to sedate the person). In some institutions, there are seclusion rooms where an individual will be placed for a period of time until their behaviour changes to the satisfaction of staff. It is always difficult to differentiate between the use and abuse of restraint and seclusion. A useful regional set of standards are those developed by the European Committee for the Prevention of Torture (CPT Standards), and monitors are advised to consult this document.

Part 15 **Habilitation and rehabilitation**

The CRPD recognises that States are under an obligation to ‘enable people with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life’ (Article 26(1)). To this end, States must develop rehabilitation services in the areas of health, employment, education and social services. Staff members should receive training on rehabilitation. The Toolkit works on the assumption that in order to get people out of institutions and into the community a range of services need to be provided. Such services would include, for example, occupational therapy and skills training. This Part asks questions to find out the extent to which all residents have access to, and are included in, rehabilitation activities.

Part 16 **Consent to treatment**

In many countries, consent to treatment is thought to consist of three main elements: information, voluntariness and functional capacity. Information means that the person needs to be provided with accurate, truthful, accessible and full information in order for him or her to come to a treatment choice, and this includes the choice to refuse treatment. Voluntariness means that the decision needs to be free from threats, pressure or other types of coercion by doctors, other professionals, family members or others. Functional capacity, a concept which is challenged by the CRPD, means that the person needs to be able to understand the information, weigh it up, and communicate – through a support network if needed – a decision.

This right to consent to medical treatment is inherent in the right to health, which can be found in Article 12 of the International Covenant on Economic, Social and Cultural Rights of 1966. The right to health is contained in Article 25 of the CRPD, a provision which sets out that ‘persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.’ Disability here clearly includes mental health problems and intellectual disability. Article 25(1) picks out sexual and reproductive health services for special attention, linking with family rights under Article 23. Article 25(d) requires healthcare services to ‘provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent.’ This is of profound importance and is reflected by the number of questions in Part 16 which probe into consent to treatment.

Part 17 **Access to physical health care**

People in mental health and social care institutions sometimes do not have the same access to general somatic health care services as those living outside these institutions. Article 25 of the CRPD provides for healthcare for people with disabilities to be delivered without discrimination on the basis of disabilities, and this means (in Article 25(1)) ‘providing persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons.’

Part 18 **Access to mental health services**

Despite improved treatment options and positive developments in psychiatric care, people with mental health problems or disability, especially when institutionalised, often experience social exclusion, stigmatisation, discrimination or the non-respect of their fundamental rights and dignity, including a lack of adequate access to psychiatric care itself. When a person is regarded as a long-term psychiatric patient, this often implies less attention by mental health staff in terms of monitoring the condition, and adjusting the treatment and rehabilitation goals. So Part 18 seeks information about the quality and frequency of access to psychiatric assessment and treatment.

Part 19 **Access to general practitioners/ family physicians**

Primary health care is the first level of health care contact, and so constitutes the first element of a continuing health care process. When provided by a general practitioner, primary health care can provide continuity of care. Part 19 therefore assesses how far such primary healthcare is properly provided for residents within the institution.

Part 20 **Access to nurses and care staff**

In practice, the primary workforce made up of nurses and care staff may be in short supply in some institutions. Sometimes nurses and care staff have excessive caseloads. Such nurses and care staff need to receive sufficient education and training as the World Health Assembly has adopted Resolution WHA59.23, urging Member States to affirm their commitment to a 10-year plan for the education and training of more health workers worldwide. Part 20 therefore assesses access to such trained nursing care.

Part 21 **Access to therapies**

Psychological, social and occupational therapies are seen in many countries as an essential component of the full range of treatments for mental health problems. Part 21 therefore asks about access to psychological, social and occupational therapies.

Part 22 **Health care records**

It is essential that health care documentation is recent and accurate, and addresses the individual's clinical status, social functioning and full range of needs. Documentation will usually need to include a specific diagnosis, where appropriate. Article 22(2) of the CRPD ensures the protection of 'privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.' In Part 22, monitors are therefore asked to assess how fresh the information is, and the level of detail included in individual health records.

Part 23 **Physical health promotion and physical illness prevention**

Many seriously disabling conditions, including cardiovascular diseases, cancer, diabetes and chronic respiratory disorders, are associated with common and preventable risk factors. For example, tobacco use, unhealthy nutrition, physical inactivity, and excessive alcohol use are major causes of physical illness. Early detection of such conditions is therefore particularly important among people in institutional settings, where such risk factors are common. Physical illness prevention will therefore include positive measures to prevent the occurrence of high blood pressure, metabolic syndrome, or high cholesterol levels. Part 23 asks monitors to assess how far such activities are undertaken on a regular and systematic basis. Appropriate checks may include: routine screenings (physical examination/investigation, blood and urine test, electro-cardiogram, chest X-ray) performed at regular intervals, with appropriate informed consent; mammograms; breast self-examination and/or breast examination by doctor; pap-tests; faecal occult blood tests; colonoscopy; flexible sigmoidoscopy; urological examinations; skin examination (skin-cancer screening); visual inspection of the mouth (the oral cavity is easily accessible for routine examination, and non medical personnel can readily detect lesions that are the precursors of carcinoma); checks for gastro-intestinal problems, diuresis and intestinal regularity, including urinary incontinence and encopresis; blood pressure; pulse rate; respiratory rate; temperature; bedsores (in bed-ridden residents).

Part 24 **Medication for physical and mental conditions**

Within psychiatric and social care institutions there must be adequate availability of all necessary medications for mental and physical conditions. The availability of such medication does not mean that it should be imposed upon people: see the right to consent to treatment in Part 16. The aspects to be monitored include the provision of such medications and how far residents are routinely given information about, and involved in, the creation of their treatment plans. This includes details of side effects, close attention to residents' personal opinions and wishes regarding medication, respect for people's preferences of type of medication, and routes of administration. Monitors may also need to assess whether the prescription of medication is consistent with safe practice, including individualised prescriptions with the signature of the responsible clinician, clear dosage and frequency. Of particular concern in institutions is over-medication, and the discretionary use of medication for sedation or restraint that is allowed to staff (see also Part 14, Restraint and seclusion).

Part 25 **Physical health assessment on admission**

The need for a thorough medical examination on admission to mental health institutions, or indeed on arrival into a social care institution, will often be a vital part of the reception process. An insufficient initial physical assessment may have detrimental long-term consequences for residents in terms of excess mortality and disability/morbidity. An admission assessment should include taking a thorough case history, physical investigation (blood pressure, radial pulse, weight, height to calculate body-mass index, waist measurement), blood and urine tests, ECG/EKG or chest X-ray.

Part 26 **Diagnosis (physical and mental)**

For physical conditions, the main international system of classification and diagnosis is the International Classification of Diseases Manual, Tenth Revision (ICD-10). For mental health problems, this system is in common use, while other practitioners and countries use the Diagnostic and Statistical Manual (DSM). A clear and written diagnosis is usually an important part of the assessment that will lead to an individualised care plan. Part 26 therefore ask monitors to assess whether a diagnosis is clearly stated in residents' clinical records. This is also important for governments to collect data and statistics, a provision contained in Article 31 of the CRPD.

Part 27 **Electro-Convulsive Therapy (ECT)**

Electro-Convulsive Therapy (ECT) remains a controversial treatment that has been the subject of substantial research in terms of its ethics, clinical indications and contra-indications, safety, effects and side-effects, and mode of action. ECT has raised clinical concerns about its serious side effects, including fractures (before the use of neuromuscular blocking agents) and cognitive (memory) impairment. Monitors will therefore need to establish whether and how ECT is used in the institution being assessed. They can, for example, ask about the use of consent, anaesthetic sedation, resuscitation equipment, and the administration of ECT in accordance with relevant protocols and national laws.

Part 28 **Alcohol, cigarettes and illegal drugs**

People with mental health problems have more physical disorders than the general population. Exposure to high risk factors such as smoking and alcohol misuse are more common among people with long-term mental health problems. Low socioeconomic status of many people with serious mental health problems may reduce their access to care for medical problems associated with alcohol, cigarettes and illegal drugs.

Part 29 **Involvement in care plans**

Service user involvement in mental health is regarded as an indicator of good practice and has evolved, in part, as a consequence of the mental health system being considered unresponsive to the needs of individual consumers, user groups and a discerning public. Contemporary standards and policy identify consumer and carer participation in the planning, implementation and evaluation of mental health services as a high priority. The CRPD echoes this philosophy by ensuring that people with disabilities are enabled to make choices about their own lives, with the help of a support network when needed (Article 12).

Part 30 **Consent to participate in research**

The CRPD makes clear in Article 15 – the provision preventing torture or cruel, inhuman or degrading treatment or punishment – that ‘no one shall be subjected without his or her free consent to medical or scientific experimentation.’ When conducting health-related research with residents in institutions, national laws and local ethical committees may set requirements upon informed consent to participate. Such requirements are likely to address providing potential participants with sufficient information to be able to judge the benefits and risks of participation; the guarantee that refusal to participate will not adversely affect their routine care; the expectation that any information gathered will be treated confidentially and that their privacy will be respected; and that if residents consent to participate in any research project, their dignity, rights, safety and wellbeing will be assured and safeguarded. Part 30 therefore assesses whether there is evidence that such protections are, or are not, provided to residents.