

# THE ITHACA TOOLKIT

for monitoring **Human Rights** and **General Health Care** in mental health and social care institutions

This publication arises from the project Institutional Treatment, Human Rights and Care Assessment (ITHACA), which has received funding from the European Union, in the framework of the Public Health Programme.

**[www.ithacastudy.eu](http://www.ithacastudy.eu)**

2010

## Acknowledgements

This publication arises from the project Institutional Treatment, Human Rights and Care Assessment (ITHACA), which has received funding from the European Union, in the framework of the Public Health Programme. The ITHACA Project and the development of the Toolkit was led by staff in five centres:

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- National Institute for Health and Welfare, Helsinki, Finland: Susanna Hietala, Jukka Hiissa, Matti Järvelä, Hannu Lindholm, Anne-Marita Ruuska, Kaisa Saavalainen, Sarianna Sallamaa, Markku Salo, Tom Stenman, Raimo Urpilainen, Kristian Wahlbeck.

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### Citation

This document should be referred to as:  
The ITHACA Project Group (2010). ITHACA Toolkit for Monitoring Human Rights and General Health Care in Mental Health and Social Care Institutions. Health Service and Population Research Department, Institute of Psychiatry, King's College London, London.

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# Section 1 **Aims of the Toolkit**

The aim of this Toolkit is to provide a complete guide to monitor human rights, including the right to health, in mental health and social care institutions.

## **Who are people with mental health problems and people with intellectual disabilities?**

The United Nations estimates that there are 650 million people worldwide who have disabilities, and 80 per cent of them live in developing countries. Among these people, a significant proportion have mental health disabilities<sup>1,2</sup> or intellectual disabilities<sup>3</sup>. Some people with intellectual disabilities also have mental health problems. Within each 'group', individual people have a wide variety of aspirations, desires and needs. Therefore, in using the terms 'people with mental health problems' and 'people with intellectual disabilities', this Toolkit does not wish to suggest that these are homogenous 'groups'.

The World Health Organisation estimates that one in four of us will have a mental health problem at some time in our lives. Given the ageing populations in many countries, the number of people with degenerative diseases such as dementia or Alzheimer's will continue to rise. Mental health issues affect most families, but yet people with mental health problems, as well as those with intellectual disabilities are often excluded from, and by, mainstream societies.

## **What are mental health and social care institutions?**

Despite the high numbers of people with mental health disabilities and intellectual disabilities, they often remain at the margins of society, vulnerable to their human rights being violated. The reasons for this are that many societies fear or pity people with a disability. Fear and pity lead to stigma, stigma to discrimination, and discrimination to abuse. Once a culture of stigma, discrimination and abuse has become entrenched, so too does resistance to change, and to reform systems to provide a range of services for people.

A significant proportion of people with intellectual disabilities and mental health disabilities are segregated from society and live for some period of their lives and/or receive care and treatment in institutions. It is these institutions, and the human rights of people in them, which are the focus of this Toolkit. People with disabilities removed from society as the result of placement in mental health institutions (such as psychiatric hospitals) and in social care institutions (such as residential care homes) are particularly vulnerable to neglect and abuse. This Toolkit has been developed with reference to the definition of an institution as 'any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.'<sup>4</sup> In practice, the ITHACA Toolkit has been developed and field tested in a wide range of different settings, for example psychiatric hospitals (sometimes mixed with neurology), psychiatric departments of general hospitals, social care institutions for people with mental health problems, residential care homes, support living settings, social care institutions for people with intellectual disabilities, rehabilitation centres, and secure psychiatric facilities. This Toolkit is therefore relevant to such institutions or residential settings of any size or scale.

<sup>1</sup> In the ITHACA Toolkit, various terms are used for people with mental health disabilities. 'People with mental health disabilities' is the term we use most often.

<sup>2</sup> Other terms used include 'service users' in a community context, 'residents' in an institutional context, 'patients' in a medical context, 'clients' in a legal context, and 'detainee' when a person is deprived of their liberty. Service 'consumers' and 'survivors' are further terms that may be used.

<sup>3</sup> Sometimes referred to as 'developmental disabilities' or 'learning disabilities'.

<sup>4</sup> Definition from the European Coalition of Community Living.

## **Why close mental health and social care institutions and develop community-based services?**

Institutions still exist in many parts of the world, despite empirical evidence demonstrating the harm caused by such facilities and the tangible benefits of living in community settings. With the advances of treatment and rehabilitation options, as well as a recognition of the value of social support, virtually all people with mental health problems and intellectual disabilities can lead lives in community settings and contribute to society. There is much evidence of the deleterious effect of institutions, but the ideology that segregation is in the best interests of the individual and of society continues to shape mental health and social care policies and services in many countries.

## **Why open mental health and social care institutions to public scrutiny?**

States must fulfil their obligations to implement the right of people with disabilities to live in the community. Whilst this obligation remains unfulfilled, States must ensure that the rights of people inside institutions are respected, protected and fulfilled. Human rights cannot be assured unless and until the cloak of invisibility, so common to institutions, is lifted. The most effective way of removing this cloak is through the active use of independent inspectorates to prevent ill-treatment. Without independent monitoring, neglect and abuse will continue with impunity, and will continue to be unnoticed and unremedied.

People with mental health and intellectual disabilities constitute the majority of residents detained in such institutions. In some institutions there are also people with hearing, visual and other disabilities as well as people with no disabilities. In some countries, political dissidents are sent to mental health institutions. People in institutions are particularly vulnerable to abuse because many of these institutions are places of detention. Inside institutions, people's ability to make decisions is taken away and sometimes residents are not allowed to decide to leave, they are deprived of legal capacity and placed under guardianship, and they are subjected to medical treatment against their will. Some people in such institutions have profound disabilities and communications disabilities, and they would find it difficult to communicate any human rights violations they are suffering. In addition, institutions are often far removed from urban centres and there are few visitors, no means of communicating with the outside world, no groups providing an advocacy service, and no State-funded lawyers to take up allegations of human rights violations.

International human rights law – such as the Optional Protocol to the United Nations (UN) Convention against Torture – demand regular and independent monitoring of people who are in places of detention. Other pieces of international human rights law – such as the UN Convention on the Rights of Persons with Disabilities – say that the rights of people with mental health disabilities and intellectual disabilities need to be monitored. The Toolkit sets out these and other standards on monitoring mental health and social care institutions.

Human rights violations can continue to occur even in States which have taken steps to shut large institutions and establish a range of services in community-based settings. For example, human rights abuses may occur in psychiatric wards in general hospitals and even in day centres and group homes in the community. The human rights of people in those settings merit close monitoring.

In parts of the world, mental health services have shifted from closed institutional care to providing a range of services in community-based settings, although quite often this has not been accompanied by sufficient transfer of resources. One of the consequences of this transformation has been that people with mental health problems and intellectual disabilities have ended up homeless or in prison. Some prisons are, in these countries, the new mental health institutions, and the human rights of people with mental health problems and intellectual disabilities in prisons should also be the focus of monitoring. Although there are already monitoring toolkits for prisons, aspects of this Toolkit can be used and adapted for such settings.

## **For whom has this Toolkit been produced?**

This Toolkit is designed to be used by groups undertaking independent human rights monitoring. These may include national inspectorate systems established under the Optional Protocol to the UN Convention against Torture; as well as monitoring bodies established by Article 33(2) of the UN Convention on the Rights of Persons with Disabilities. It can also be used by national human rights institutions and ombudsman offices. It is also hoped that the Toolkit will be of benefit to independent non-governmental organisations who wish to carry out monitoring, and to supranational monitoring bodies such as the Council of Europe's Committee for the Prevention of Torture, and the United Nations Sub-Committee for the Prevention of Torture. We particularly encourage groups consisting of mental health service users, as well as those for and of people with intellectual disabilities, to undertake monitoring of institutions and make recommendations to the relevant authorities.

## Which human rights should be monitored?

This Toolkit has been designed to refer directly to the UN Convention on the Rights of Persons with Disabilities (CRPD), which promotes the right to live and receive services in the community (see Article 19 CRPD). All countries which ratify the CRPD are under an obligation to take steps to implement this Article, and all the other Articles of the Convention. However, as long as institutions exist, this Toolkit provides guidance on the range of human rights violations which may occur in institutions and as a result of institutionalisation.

## Roadmap to the Toolkit

*Section 2* of the Toolkit outlines some basics about human rights. It introduces human rights standards of relevance to the topic of monitoring mental health and social care institutions, and sets out some mechanisms of human rights protection. It introduces the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

*Section 3* provides background information to conduct the general health care monitoring. This provides information on topics of particular concern to the general health of persons with mental health disabilities.

*Section 4* of the Toolkit turns to the practicalities of carrying out human rights monitoring in mental health and social care institutions. It first looks at the purpose of human rights monitoring and how monitoring can be followed up with other methods, including advocacy and campaigning, awareness-raising, capacity-building, motivating others to participate in monitoring, raising an organisation's profile, and litigation.

*Section 5* looks at the principles of human rights monitoring which include doing no harm, the necessity of carrying out regular monitoring, the need to demonstrate independence, building a credible team, collecting reliable information, adopting an inquisitive mindset, storing information securely and keeping contact with sources.

*Section 6* addresses the practicalities of how to conduct human rights monitoring. This section includes how to conduct interviews with people with mental health problems and intellectual disabilities, how to review documentation, how to make observations, and how to record information.

*Section 7* then sets out the ten steps of human rights monitoring, providing questions that monitors will need to answer before starting out on the monitoring process.

*Section 8* sets out the issues which human rights monitors may want to look at when conducting a monitoring visit. The section is a guide to the prompt questions presented in 30 Parts within *Section 9* and describes how the questions refer to the CRPD in each Part of the data collection.

Finally, *Section 9* is a list of prompt questions to be used during data collection. The questions are presented in 30 Parts. Monitors may like to have this with them on monitoring visits.

## Section 2 What are human rights?

Human rights are entitlements set out in international law (for example, the International Covenant on Civil and Political Rights) or national law (for example, a Constitution or a specific law). The State is the primary 'body' which has a responsibility to respect, protect and fulfil full enjoyment of human rights. The word 'State' includes central government, local government, other governmental and quasi-governmental agencies, as well as courts and tribunals. Governments have an obligation to ensure that 'non-State actors' such as private hospitals, private prisons, private security companies and so on, also uphold the rights of persons for whom they are responsible.

Under international law, States must respect, protect and fulfil human rights. The obligation to respect means that States must not interfere with, or curtail the enjoyment of, human rights. To give one example, States must not interfere with the right to vote of persons in social care institutions. The obligation to protect requires States to protect individuals and groups against human rights abuses. An example of this is that institutions must ensure that there are procedures in place to prevent violence and abuse. The obligation to fulfil means that States must take positive action to facilitate the enjoyment of basic human rights. An example of this is that a mental health professional needs to provide written and verbal information to a person in a language and format which the person understands before asking that person to consent to, or refuse, any type of treatment.

People with mental health problems or intellectual disabilities may be exposed to a range of issues which can be thought of in human rights terms. Violation of these rights are likely to exacerbate any pre-existing mental health problems, rather than make them better. Some human rights abuses are obvious: a male nurse raping female psychiatric patients, for example, is an issue for which it is easy to point a finger at a perpetrator who carries out the abuse with intent. However, many or most human rights abuses in mental health and social care institutions are structural in nature, and it may be that there is no person or group of people at the institution who are directly responsible for the abuses.

Instead, systemic violations may be the result of a faulty law or policy, a law or policy which has not been implemented at all or properly, a national or regional or institutional culture, systemic underfunding of services, or funding the wrong type of service – for example a large psychiatric hospital instead of community-based mental health services.

It is particularly useful in these instances to remember that 'the State' has obligations to respect, protect and fulfil human rights for all people in its territory without discrimination. Given that many human rights violations happen without any intention to cause harm, it is important to remember that a human rights monitoring venture is not about demonising service-providers, but rather about objectively and accurately measuring the reality against human rights standards.

The Section below outlines international and regional human rights standards and mechanisms of particular relevance to people with mental health and intellectual disabilities, and pays particular attention to the United Nations Convention on the Rights of Persons with Disabilities which is the framework used for this Toolkit.

### 2.1 Human rights standards

In 1948, the United Nations (UN) adopted the Universal Declaration of Human Rights, which gave birth to the modern international human rights movement. Since then, other conventions, declarations, directives and recommendations have been adopted by the UN and other international bodies. The UN is made up of most of the world's governments, so human rights have been agreed by States, rather than imposed upon them from the outside. The newest UN human rights treaty is the UN Convention on the Rights of Persons with Disabilities (CRPD). As noted above, this Convention constitutes the framework for this Toolkit and is discussed in further detail in Section 3.

Services for people with mental health disabilities or intellectual disabilities sometimes involve the imposition of certain limitations or restrictions on people's rights. For example, domestic law in many States allows certain people to detain a person who has been assessed as having a mental health problem which results in a risk to that person's or another person's health or safety. Laws in many countries allow doctors to administer medication against a person's will. These drugs can have an impact (positive or negative) on the person's physical and mental well-being. There is therefore an interface between medical issues and human rights issues.

Prior to the CRPD, a number of UN instruments were adopted to protect and promote the rights of persons with disabilities, sometimes focusing specifically on people with mental health problems and sometimes on people with intellectual disabilities.

These include:

- Declaration on the Rights of Mentally Retarded Persons (1971)<sup>5</sup>
- Declaration on the Rights of Disabled Persons (1975)<sup>6</sup>
- World Programme of Action concerning Disabled Persons (1982)<sup>7</sup>
- Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (1991)<sup>8</sup>
- Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993)<sup>9</sup>

These documents are not legally binding, but they expressed moral and political commitment by States at the time they were adopted, and have been used as guidelines to enact legislation or to formulate policies concerning persons with disabilities, and by courts to interpret laws. However, these documents are not uncontroversial. They were adopted by politicians with little input from civil society, and in particular, people with mental health problems and people with intellectual disabilities. Some provisions of the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care weaken the principle of consent to treatment so as to render the principle meaningless and provide a lesser degree of protection than the legally-binding CRPD.<sup>10</sup>

There are nine core UN human rights treaties. Each one is legally-binding on a State which has ratified it. All are relevant for the rights of persons with disabilities, and one – the CRPD – is of specific relevance to people with disabilities. The two primary treaties which flow from the non-legally binding Universal Declaration of Human Rights (UDHR)<sup>11</sup> are the International Covenant on Economic, Social and Cultural Rights ('ICESCR', 1966)<sup>12</sup> and the International Covenant on Civil and Political Rights ('ICCPR', 1966)<sup>13</sup>, which set out a number

of rights, including the right to non-discrimination. Together with the UDHR these three documents make up the 'international bill of rights', and most States have ratified both the ICCPR and the ICESCR<sup>14</sup>.

There are also human rights conventions focusing on rights important for particular 'groups', such as racial minorities (1965)<sup>15</sup> women (1979)<sup>16</sup>, children (1989)<sup>17</sup> and migrant workers (1990)<sup>18</sup>. As noted, the newest treaty is the 2006 Convention on the Rights of Persons with Disabilities (CRPD), which entered into force upon its twentieth ratification in May 2008<sup>19</sup>.

The UN Convention against Torture (1984)<sup>20</sup> establishes substantive protection against torture, inhuman, cruel or degrading treatment or punishment. It is supplemented by the Optional Protocol to the Convention against Torture (commonly known as OPCAT) which, as noted above, does not establish any substantive rights, but establishes an international monitoring body of places of detention known as the UN Sub-Committee for the Prevention of Torture (SPT), and obliges States to establish or designate national preventive mechanism(s) which should monitor the rights of people in places of detention, including prisons and police stations, as well as mental health institutions and social care institutions<sup>21</sup>.

All human rights treaties include a provision protecting against discrimination and all of them are understood to refer to disability implicitly as a ground of discrimination, making it clear that persons with disabilities should not be discriminated against in the application of any right. However, until the CRPD, only the Convention on the Rights of the Child explicitly recognized disability as a ground of discrimination.

We recommend that everyone involved in human rights monitoring gains a in-depth understanding of these core instruments. One does not need to be a lawyer or a specialist to do so, and there are lots of easy-to-read human rights materials available.

<sup>5</sup> Adopted by General Assembly resolution 2856 (XXVI) on 20 December 1971

<sup>6</sup> Adopted by General Assembly resolution 3447 (XXX) on 9 December 1975

<sup>7</sup> Resolution contained in United Nations document A/37/51, Official Records of the General Assembly, Thirty-seventh Session Supplement No. 51 on 3 December 1982

<sup>8</sup> Adopted by General Assembly Resolution 46/119 on 17 December 1991

<sup>9</sup> Adopted by General Assembly resolution 48/96 on 20 December 1993

<sup>10</sup> For a commentary on the evolving human rights provisions, see a special report on torture and disability by the UN Special Rapporteur on Torture: *Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, Manfred Nowack, to the UN General Assembly, 28 July 2008, Ref A/63/175, available at [www2.ohchr.org/english/issues/disability/docs/torture/A\\_63\\_175\\_en.doc](http://www2.ohchr.org/english/issues/disability/docs/torture/A_63_175_en.doc) (accessed 18 January 2009)

<sup>11</sup> Adopted by General Assembly resolution 217A (III) on 10 December 1948

<sup>12</sup> Adopted by General Assembly resolution 2200A (XXI) on 16 December 1966

<sup>13</sup> Adopted by General Assembly resolution 2200A (XXI) on 16 December 1966

<sup>14</sup> For more information on which States have ratified which treaties, see <http://tb.ohchr.org> (accessed 19 January 2009).

<sup>15</sup> International Convention on the Elimination of All Forms of Racial Discrimination adopted by General Assembly resolution 2106 (XX) on 21 December 1965

<sup>16</sup> Convention on the Elimination of All Forms of Discrimination against Women adopted by General Assembly resolution on 18 December 1979

<sup>17</sup> Convention on the Rights of the Child adopted by General Assembly resolution 44/25 on 20 November 1989

<sup>18</sup> International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families adopted by General Assembly resolution 45/158 of 18 December 1990

<sup>19</sup> For more information on the CRPD, see [www.un.org/disabilities](http://www.un.org/disabilities) (accessed 19 January 2009)

<sup>20</sup> Adopted by General Assembly resolution 39/46 of 10 December 1984

<sup>21</sup> For more information on human rights treaties, see [www.ohchr.org](http://www.ohchr.org) (accessed 19 January 2009)

## 2.2 Regional human rights standards and mechanisms

As well as UN mechanisms, there are several regional groupings which have formulated their own regional standards. These are also important sources of human rights standards. Some of them have their own mechanisms of enforcement. By this, we mean a variety of ways in which human rights implementation can be assessed: judicial bodies to which individual cases can be brought; committees of experts which monitor State compliance; committees of experts which decide upon collective complaints; and investigative mechanisms. Again, it is important for human rights monitors to gain a familiarity of the instruments applicable to their region. Some of the key regional human rights instruments and their respective monitoring mechanisms are:

### Africa

■ African Charter on Human and Peoples' Rights (1981). The African Commission on Human and Peoples' Rights, set up in 1987 and based in Banjul, Gambia, provides oversight. A protocol to the Charter was adopted in 1998 and when it came into effect, established an African Court on Human and Peoples' Rights. The African system also has the African Commission on Human Rights which carries out important functions<sup>22</sup>.

■ African Charter on the Rights and Welfare of the Child (1990), under the Organisation of African Unity. This mirrors much of the UN Convention on the Rights of the Child<sup>23</sup>.

### Americas

■ American Convention on Human Rights (1969). The bodies responsible for overseeing compliance with the Convention are the Inter-American Commission on Human Rights and the Inter-American Court of Human Rights, both of which are organs of the Organisation of American States<sup>24</sup>.

■ The American system also has the Inter-American Convention on the Elimination of all Forms of

Discrimination against Persons with Disabilities (2001) which the first treaty on disability prior to the CRPD<sup>25</sup>.

■ Inter-American Convention to Prevent and Punish Torture (1985), an instrument also of the Organisation of American States<sup>26</sup>.

■ Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Woman (1994) also under the Organisation of American States<sup>27</sup>.

### Arab States

■ Arab Charter on Human Rights (2004). Adopted by the Council of the League of Arab States, and entered into force in 2008<sup>28</sup>.

### Europe

■ Convention for the Protection of Human Rights and Fundamental Freedoms (1950). Commonly known as the 'European Convention on Human Rights'. The European Court of Human Rights, based in Strasbourg, France, interprets the Convention when deciding on individual applications brought to it by individuals from the 47 countries of the Council of Europe. The Court has decided on a wealth of cases concerning mental health disability<sup>29</sup>.

■ European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (1987). This Convention does not establish any substantive rights, but sets up the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT for short). The CPT visits places of detention – including mental health and social care institutions – in all Council of Europe Member States. The resultant reports become public when the government consents to their publication<sup>30</sup>.

■ Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (1997). Although this is a Convention and is legally binding, there is no monitoring mechanism<sup>31</sup>.

<sup>22</sup> See [www.africa-union.org/root/au/Documents/Treaties/Text/Banjul%20Charter.pdf](http://www.africa-union.org/root/au/Documents/Treaties/Text/Banjul%20Charter.pdf) for more information (accessed 19 January 2009)

<sup>23</sup> See [www.africa-union.org/Official\\_documents/Treaties\\_%20Conventions\\_%20Protocols/A.%20C.%20ON%20THE%20RIGHT%20AND%20WELF%20OF%20CHILD.pdf](http://www.africa-union.org/Official_documents/Treaties_%20Conventions_%20Protocols/A.%20C.%20ON%20THE%20RIGHT%20AND%20WELF%20OF%20CHILD.pdf) for more information (accessed 19 January 2009)

<sup>24</sup> See [www.oas.org/juridico/English/treaties/b-32.html](http://www.oas.org/juridico/English/treaties/b-32.html) for more information (accessed 19 January 2009)

<sup>25</sup> See [www.oas.org/juridico/english/treaties/a-65.html](http://www.oas.org/juridico/english/treaties/a-65.html) for more information (accessed 19 January 2009)

<sup>26</sup> See [www.oas.org/juridico/english/treaties/a-51.html](http://www.oas.org/juridico/english/treaties/a-51.html) for more information (accessed 19 January 2009)

<sup>27</sup> See [www.oas.org/juridico/english/treaties/a-61.html](http://www.oas.org/juridico/english/treaties/a-61.html) for more information (accessed 19 January 2009)

<sup>28</sup> See <http://www1.umn.edu/humanrts/instree/arabhrcharter.html> for more information (accessed 19 January 2009)

<sup>29</sup> See [www.echr.coe.int](http://www.echr.coe.int) for more information (accessed 19 January 2009). Mental Disability Advocacy Center (2007) *Summaries of Mental Disability Cases Decided by the European Court of Human Rights* downloadable from [www.mdac.info](http://www.mdac.info). On the Court's jurisprudence, see Bartlett P, Lewis O and Thorold O (2006) *Mental Disability and the European Convention on Human Rights*, Martinus Nijhoff, Brill Publishing, The Netherlands.

<sup>30</sup> See [www.cpt.coe.int](http://www.cpt.coe.int) for more information (accessed 19 January 2009)

<sup>31</sup> See <http://conventions.coe.int/Treaty/EN/Treaties/html/164.htm> for more information (accessed 19 January 2009)

■ **European Social Charter – Revised (1996).** The European Committee on Social Rights reviews a State's compliance, and some organisations are entitled to lodge 'collective complaints' on specific issues<sup>32</sup>.

■ **The Charter of Fundamental Rights of the European Union.** The Charter only applies to European Union (EU) member states when they are implementing EU law and is enforceable in EU courts.

Within the European region there are also some soft-law instruments which are of relevance. These documents are not legally binding on States, but have been agreed unanimously by the Committee of Ministers of the Council of Europe, which is comprised of the governments of all of the Member States of the Council of Europe:

- **Recommendation Rec(1999)4** of the Committee of Ministers to member states on principles concerning the legal protection of incapable adults.
- **Recommendation Rec(2004)10** of the Committee of Ministers to member states concerning the protection of the human rights and dignity of persons with mental disorder.
- **Recommendation Rec(2009)11** of the Committee of Ministers to member states on principles concerning continuing powers of attorney and advance directives for incapacity.
- **Recommendation CM/Rec(2009)3** of the Committee of Ministers to member states on monitoring the protection of human rights and dignity of persons with mental disorder.
- **Recommendation Rec(2010)2** of the Committee of Ministers to member states on deinstitutionalisation and community living of children with disabilities.

The following documents are relevant to the Toolkit's ambit and have been adopted by the Parliamentary Assembly of the Council of Europe:

- **Resolution 1642 (2009)1** Access to rights for people with disabilities and their full and active participation in society.
- **Recommendation 1854 (2009)1** Access to rights for people with disabilities and their full and active participation in society.

## 2.3 UN Convention on the Rights of Persons with Disabilities (CRPD)

The UN Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol were adopted on 13 December 2006 by the UN General Assembly, and were opened for signature on 30 March 2007. The CRPD is the first comprehensive human rights treaty of the twenty-first century and is the first human rights convention to be open for signature by 'regional integration organisations' (such as the European Union). It is the fastest human rights treaty ever to be adopted, having been negotiated during eight sessions by an Ad Hoc Committee of the General Assembly from 2002 to 2006.

The CRPD is a human rights instrument with an explicit social development dimension. It adopts a broad approach to the concept of disability and reaffirms that all persons with all types of disabilities are holders of all human rights and fundamental freedoms. It clarifies and qualifies how specified categories of rights apply to persons with disabilities and identifies areas where the State must ensure that adjustments (known as reasonable accommodations) be made for persons with disabilities to effectively exercise their rights. As noted above, this Toolkit takes the CRPD as its framework but does not attempt to offer a comprehensive analysis of the CRPD as this is available elsewhere. We recommend that monitors are familiar with the CRPD provisions and recommend as a starting point the United Nations website ([www.un.org](http://www.un.org)) which contains materials which are available in a variety of languages about the Convention.

### 2.3.1 'Persons with disabilities'

The CRPD does not offer a definition of disability. Instead, the preamble recognizes that 'disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others'<sup>33</sup>. Article 1 of the Convention defines person rather than disability, saying that '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.' From examining the official discussions (travaux préparatoire) which took place during the drafting of the Convention, it is clear that people with mental health problems and people with intellectual disabilities fall within the CRPD's ambit.

Several elements of these provisions are notable. First, there is recognition that 'disability' is an evolving concept resulting from attitudinal and environmental

<sup>32</sup> See [www.coe.int/t/dghl/monitoring/socialcharter/default\\_en.asp](http://www.coe.int/t/dghl/monitoring/socialcharter/default_en.asp) for more information (accessed 19 January 2009)

<sup>33</sup> Preambulatory paragraph (e) of the CRPD

barriers hindering the participation of persons with disabilities in society. Consequently, the notion of ‘disability’ is not fixed and can alter, depending on the prevailing social, economic and political context.

Second, the CRPD views disability not as a medical condition, but rather as a result of the interaction between negative attitudes or an unwelcoming environment with the condition of particular persons. By dismantling attitudinal, environmental and legal barriers rather than focusing on fixing a problem with the individual person, people with disabilities are able to participate as active members of society and enjoy the full range of human rights. This is part of the paradigm shift which the Convention seeks – explained in more detail in the following section.

Third, the Convention does not restrict coverage to particular persons. Rather, the definition contains the word ‘includes’, which means that the list of ‘long-term physical, mental, intellectual and sensory disabilities’ is non-exhaustive.

### 2.3.2 Innovations of the CRPD

The Convention represents a so-called paradigm shift, reflecting progressive attitudes and approaches to persons with disabilities. It moves away from the medical model of disability which views people with disabilities as objects (of treatment, management, protection, charity and sometimes pity and fear), and towards the social model of disability which regards people with disabilities as subjects of the full range of human rights on an equal basis with others, and where people’s capacity to make decisions is presumed. Two substantive areas demonstrate the ‘paradigm shift’. The first is legal capacity and the second is the right to live in the community.

Legal capacity is addressed in Article 12 of the Convention and has been the subject of extensive debate. It is an area highlighted for concern by disabled people’s organisations, legal experts, NGOs and the High Commissioner for Human Rights as requiring a special focus for implementation<sup>34</sup>. In many countries, people with disabilities are not viewed as people before the law<sup>35</sup>. In others, the law gives judges the authority to order a person’s legal capacity to be removed completely, or restricted partially, solely on the basis of a diagnosis of a mental health or intellectual disability. Once legal capacity is removed, all legally relevant decisions are taken

by someone else, a guardian. Human rights abuses pervade the process for removing or restricting legal capacity, and a range of human rights are also removed completely: the right to manage one’s own finances, the right to decide where to live, the right to vote, the right to marry and have a family, the right to work. The CRPD’s paradigm shift puts an end to the removal of rights by detailing that everyone has legal capacity, and that States are under an obligation to provide support to people who need assistance in decision-making.

Supported decision-making is an alternative to substitute decision-making such as guardianship. The presumption in supported decision-making is always in favour of the person with a disability who will be affected by the decision. The individual is the decision-maker; the supporters explain the issues, when necessary, and interpret the will and preferences of the individual<sup>36</sup>.

A second example to demonstrate the paradigm shift can be found in Article 19 on living independently and being included in the community. In this provision the CRPD reaffirms that living in the community is an inalienable right not subject to proving one’s ‘ability’, ‘eligibility’ or ‘entitlement’. In some cases, support services may be needed, and the issue then becomes how to facilitate living independently and inclusion in the community. The right supports the direction of policy in many countries of establishing a range of services in community settings, and provides a right for everyone to have the ‘opportunity 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’ (Art. 19(a)). In addition, ‘Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs’, thus making available regular services (whether that be housing, day care, homeless shelters, or transportation, to name just a few issues, to be made available to persons with mental health problems and intellectual disabilities.

<sup>34</sup> International Disability Alliance, *Contribution to the Office of the United Nations High Commissioner for Human Rights thematic study to enhance awareness and understanding of the Convention on the Rights of Persons with Disabilities, focusing on legal measures key for the ratification and effective implementation of the Convention*, 15 September 2008, available at, [www.daisy.org/news/attachments/IDA-CRPD-Forum-Submission0809-15.doc](http://www.daisy.org/news/attachments/IDA-CRPD-Forum-Submission0809-15.doc) (accessed 19 January 2009)

<sup>35</sup> See Article 12(1)

<sup>36</sup> For more information, see *From Exclusion to Equality: Realising the Rights of Persons with Disabilities. Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol*, United Nations 2007, available at [www.un.org/disabilities](http://www.un.org/disabilities)

### 2.3.3 CRPD mechanisms

The Toolkit uses the CRPD provisions as the basis upon which rights can be monitored inside mental health and social care institutions. The CRPD also contains provisions which establish a national monitoring mechanism and an international monitoring mechanism. Monitors may wish to learn more about these mechanisms in order to engage with them when they have produced monitoring reports. In brief, the CRPD provides for an independent body (or bodies) at domestic level which has the duty to promote the rights of persons with disabilities, protect their rights, and monitor the implementation of the Convention. These bodies would naturally be interested in what is happening to persons with mental health problems and intellectual disabilities in institutions<sup>37</sup>.

At the international level, the CRPD sets up a new UN treaty body called the Committee on the Rights of Persons with Disabilities. The Committee is comprised of 18 experts who are nominated by governments but who are not supposed to represent their governments<sup>38</sup>. The Committee evaluates reports submitted by States party to the Convention (and shadow, or alternative reports submitted by non-governmental organisations)<sup>39</sup>. The Committee also has a quasi-judicial role in considering individual complaints submitted by people who allege that they have suffered a violation of one or more of the CRPD provisions in a State which has ratified the CRPD and its Optional Protocol<sup>40</sup>. Before taking a case to the Committee, a person needs to first seek remedies through the domestic legal system.

<sup>37</sup> See Article 33(2) of the CRPD, and note that Article 33(3) ensures that persons with disabilities and their representative organisations are fully involved in the Convention monitoring process

<sup>38</sup> See Article 34 of the CRPD

<sup>39</sup> See Articles 35 and 36 of the CRPD

<sup>40</sup> See Optional Protocol to the CRPD

## Section 3 What is general health care?

### 3.1 The framework used for general health care

Monitoring the health care provided to people with mental health disabilities is imperative to gain a full picture of the human rights situation experienced by this sometimes vulnerable population. The Council of Europe issued a recommendation on monitoring the human rights of persons with mental disorders and included the promotion of health care in its eight key principles<sup>41</sup>. This Toolkit adopts the framework that Paul Hunt and Judith Mesquita<sup>42</sup> applied to mental health disabilities based on the framework developed in General Comment 14 on the right to highest attainable standard of health. The central protections and entitlements of this right derive from the International Covenant on Economic, Social and Cultural Rights and are enshrined in other international human rights documents, including in Article 25 of the Universal Declaration of Human Rights as well as the CRPD. The 'Right to Health' is not the right to be healthy, but includes the right to the immediate amenities relating to health, particularly safe and effective health care, but also to a society which provides the best chances for good health for all people<sup>43</sup>. This includes access to prevention, control of diseases and appropriate sanitation.

The 'Right to Health Framework' examines issues concerning health care using four constructs: availability, accessibility, acceptability and quality (AAAQ). The diagram on page 14 illustrates the utility and application of this Framework to a general health care monitoring process. In this diagram, the Framework is applied to understand and explore the example of smoking cessation programmes. Moving through the steps of the AAAQ Framework, the monitor can understand and document exactly how these programmes work in that particular context.

We start with availability. Are smoking cessation programmes available? This is most likely a 'yes or no' question. It is imperative to move on through the Framework to gather the full picture.

Within the construct of accessibility are the key areas of geographic, economic, information and non-

discrimination. Questions for these areas include: Are the programmes provided nearby? Are they prohibitively expensive? How do people find out about them? Are all people offered access to these programmes regardless of sex, ethnicity, religion, etc?

From there, the Framework moves to issues of acceptability. How are these programmes adapted to be acceptable to people of different ethnic, sex, sexuality, religious or political backgrounds?

Finally, the Framework concludes with exploring the quality of the services or care. The series of questions generated in this construct should aim to explore the current quality as well as understand the mechanisms by which that quality is assessed, improved upon or complained about. The 'Right to Health Framework' can be a very helpful guide in developing the inquisitive mind referenced in the human rights monitoring section (see Section 2). While exploring the questions related to general health care, the monitors should hold this Framework in their mind and ask questions from each of the broad areas. Completion of this Framework results in a holistic and comprehensive appreciation of each relevant general health care issue.

To implement this 'Right to Health Framework', member States should, taking into account available resources, take measures:

- to provide a range of services of appropriate quality to meet the mental health needs of persons with mental disorder, taking into account the differing needs of different groups of such persons, and to ensure equitable access to such services;
- to make alternatives to involuntary placement and to involuntary treatment as widely available as possible;
- to ensure sufficient provision of hospital facilities with appropriate levels of security and of community-based services to meet the health needs of persons with mental disorder involved with the criminal justice system;
- to ensure that the physical health care needs of persons with mental disorder are assessed and that they are provided with equitable access to services of appropriate quality to meet such needs.

<sup>41</sup> Council of Europe. Recommendation CM/Rec(2009)3 of the Committee of Ministers to member states on monitoring the protection of human rights and dignity of persons with mental disorder (adopted by the Committee of Ministers on 20 May 2009 at the 1057th meeting of the Ministers' Deputies)

<sup>42</sup> Hunt P, Mequita J (2006) *Mental Disabilities and the Human Right to the Highest Attainable Standard of Health*. Human Rights Quarterly, 28: 332-356.

<sup>43</sup> [www2.ohchr.org/english/issues/health/right/](http://www2.ohchr.org/english/issues/health/right/) (accessed on April 20, 2010)

| The Right to Health Framework: Example: Smoking Cessation Programmes   | CESCR:Comment No. 14 |
|--|----------------------|
| <p>Using a policy perspective, we can evaluate these freedoms and entitlements based on the following criteria:</p>  |                      |
| <div style="display: flex; justify-content: space-between;"> <div style="width: 60%;"> <p><b>Availability</b> 1.</p> <ul style="list-style-type: none"> <li>Are smoking cessation programmes available?</li> <li>If these programmes do exist, when did they start?</li> </ul> <p><b>Accessibility</b></p> <ul style="list-style-type: none"> <li>How do people access them?</li> <li>Who does not use them? Why?</li> </ul> <p><b>Geographic</b></p> <ul style="list-style-type: none"> <li>Where are they located?</li> <li>How far is that from their homes?</li> </ul> <p><b>Economic</b></p> <ul style="list-style-type: none"> <li>How much do they cost?</li> <li>Is this prohibitively expensive?</li> </ul> <p><b>Information</b></p> <ul style="list-style-type: none"> <li>How do people find out about the programmes?</li> <li>What information is provided with these programmes?</li> </ul> <p><b>Without discrimination</b></p> <ul style="list-style-type: none"> <li>Who is prohibited from taking part?</li> <li>Who accesses them?</li> </ul> <p><b>Acceptability</b> 3.</p> <ul style="list-style-type: none"> <li>What minority populations are present within this setting?</li> <li>What measurements have been taken to make them culturally acceptable to indigenous and/or minority populations?</li> </ul> <p><b>Quality</b> 4.</p> <ul style="list-style-type: none"> <li>How are they evaluated/monitored?</li> <li>How effective are they?</li> <li>What is the structure of the programme?</li> <li>Who runs them?</li> <li>How does it work?</li> </ul> </div> <div style="width: 35%; padding-left: 20px;"> <p>Entitlements: considered an entitlement as part of support services.</p> </div> </div> <div style="margin-top: 20px;"> <p><b>If we simply ask about availability, we miss the rest of the picture. This Framework will answer the natural progression of questions once you have the answers to the available question</b></p> </div> <div style="margin-top: 20px;"> <p>These questions are not exhaustive but illustrative. The Framework may not apply for all topics but it is effective in developing a structured way of evaluating topics and issues.</p> </div> |                      |

### 3.2 Health promotion and illness prevention

Before considering the detection and treatment of physical and mental illnesses, it is important to consider what measures are needed (in institutions in relation to this ITHACA Toolkit) to promote health and to prevent illness<sup>44,45,46,47,48</sup>. Many seriously disabling conditions, including cardiovascular diseases, cancer, diabetes and

chronic respiratory disorders as discussed below, are associated with common and preventable risk factors. For example, tobacco use, unhealthy nutrition<sup>49,50</sup>, physical inactivity, and excessive alcohol use are major causes of physical illness<sup>51,52</sup>. Physical illness prevention will therefore include positive measures to prevent the occurrence of, for example, high blood pressure, metabolic syndrome, or high cholesterol levels.

<sup>44</sup> Zechmeister I, Kilian R, McDaid D. *Is it worth investing in mental health promotion and prevention of mental illness? A systematic review of the evidence from economic evaluations*. BMC Public Health 2008; 8:20

<sup>45</sup> Wilhelmsson S, Lindberg M. *Prevention and health promotion and evidence-based fields of nursing - a literature review*. Int J Nurs Pract 2007 Aug; 13(4): 254-65

<sup>46</sup> Pelletier KR. *A review and analysis of the health and cost-effective outcome studies of comprehensive health promotion and disease prevention programs at the worksite: 1993-1995 update*. Am J Health Promot 1996 May; 10 (5):380-8.

<sup>47</sup> Saxena S, Garrison P. *Mental Health Promotion: Case Studies from Countries*. Geneva: World Health Organisation; 2004

<sup>48</sup> Hosman C, Jane-Llopis E, Saxena S (eds). *Prevention of mental disorders: effective interventions and policy options*. Oxford: Oxford University Press, 2006.

<sup>49</sup> Treasure J, Williams K. *Nutrition and mental health*. Clin Med 2004 Sep; 4(5): 408-10.

<sup>50</sup> Kates N, Crustolo AM, Farrar S, Nikolaou L, Ackerman S, Brown S. *Mental health care and nutrition. Integrating specialist services into primary care*. Can Fam Physician 2002 Dec; 48: 1898-903.

<sup>51</sup> Penedo FJ, Dahn JR. *Exercise and well-being: a review of mental and physical health benefits associated with physical activity*. Curr Opin Psychiatry 2005 Mar; 18(2): 189-93.

<sup>52</sup> Glenister D. *Exercise and mental health: a review*. J R Soc Health 1996 Feb; 116(1): 7-13.

The importance of such promotion and prevention activities is reflected in a number of EU policy documents such as the White Paper *A Strategy for Europe on Nutrition, Overweight and Obesity related health issues*<sup>53</sup>, and the Green Paper *Promoting healthy diets and physical activity: a European dimension for the prevention of overweight, obesity and chronic diseases*<sup>54</sup>, dealing with the general population and vulnerable groups such as children and the poor.

In relation to people with mental health disabilities and intellectual disabilities, despite the EU and WHO policy emphasis demonstrated in the Mental Health Action Plan for Europe and the Mental Health Declaration for Europe adopted in Helsinki in 2005<sup>55,56</sup> in all EU States, there is no co-ordinated approach to general health promotion or to illness prevention for such groups of people. To take breast cancer as just one example, the WHO promotes breast cancer control within the context of national cancer control programmes that are integrated into non-communicable diseases and other related problems. Comprehensive cancer control involves primary prevention, early detection, diagnosis and treatment, rehabilitation and palliative care. Raising general public awareness on the breast cancer problem and the mechanisms to control, as well as advocating for appropriate policies and programmes, are key strategies of population-based breast cancer control. These issues apply at least as much to people within institutions as to the general population<sup>57</sup>. Health promotion activities targeted at the people in such institutions therefore need to be carefully monitored (see Part 23, Sections 8 and 9).

### 3.3 Lifestyle factors affecting general health

Several lifestyle factors adversely affect the physical health of people with mental health disabilities and intellectual disabilities<sup>58,59</sup>. People with mental health disabilities and intellectual disabilities have relatively low rates of exercise, along with higher rates of obesity, both of which contribute towards heart disease<sup>60,61</sup>. People within mental institutions tend to have a series of higher risk factors for physical illnesses including less awareness of health promotion, high rates of smoking<sup>62</sup>, medication side-effects (including, for example, weight gain and cardiac abnormalities), inadequate detection by staff of physical disorders, and poorer quality health care because of stigmatising attitudes of health care staff<sup>63</sup>. Poor access to healthy diet and lack of physical exercise opportunities contribute further to high blood pressure, high plasma cholesterol and triglycerides, diabetes, obesity and metabolic risk factors often referred to as the metabolic syndrome<sup>64</sup>. The prevalence of smoking among some groups of people with mental health problems, for example, schizophrenia, exceeds that in the general population (75-92 per cent v. 30-40 per cent). This high rate of smoking means that such people are at greater risk of experiencing the associated detrimental effects such as cardiovascular disease and respiratory morbidity and mortality.

Although most of these risk factors are modifiable, people with mental health disabilities and intellectual disabilities have benefited less from the recent favourable trends in cardiovascular disease than the general population<sup>65,66</sup>. However, there is growing evidence of the existence of health-promotion interventions that may enhance the physical health, if fully implemented and adapted to the specific characteristics of such groups<sup>67</sup>. Particular aspects of residents' lifestyles should be assessed (Sections 8 and 9, Part 28) in relation to alcohol, cigarettes and illegal drug use.

<sup>53</sup> [http://ec.europa.eu/health/ph\\_determinants/life\\_style/nutrition/keydocs\\_nutrition\\_en.htm](http://ec.europa.eu/health/ph_determinants/life_style/nutrition/keydocs_nutrition_en.htm)

<sup>54</sup> [http://ec.europa.eu/health/ph\\_determinants/life\\_style/nutrition/documents/nutrition\\_gp\\_en.pdf](http://ec.europa.eu/health/ph_determinants/life_style/nutrition/documents/nutrition_gp_en.pdf)

<sup>55</sup> World Health Organisation. *Mental Health Action Plan for Europe*. Copenhagen: World Health Organisation; 2005.

<sup>56</sup> [www.euro.who.int/document/MNH/edoc06.pdf](http://www.euro.who.int/document/MNH/edoc06.pdf)

<sup>57</sup> Bettinghaus EP. *Health promotion and the knowledge-attitude-behaviour continuum*. Preventive Medicine 1986;(15):475-91

<sup>58</sup> Osborn DP, Nazareth I, King MB. *Physical activity, dietary habits and Coronary Heart Disease risk factor knowledge amongst people with severe mental illness: A cross sectional comparative study in primary care*. Soc Psychiatry Psychiatr Epidemiol 2007 Aug 24

<sup>59</sup> Bradshaw T, Lovell K, Harris N. *Healthy living interventions and schizophrenia: a systematic review*. J Adv Nurs 2005 Mar: 49(6): 634-54

<sup>60</sup> McCreddie RG. *Diet, smoking and cardiovascular risk in people with schizophrenia: descriptive study*. Br J Psychiatry 2003 Dec: 183: 534-9.

<sup>61</sup> Brown S, Inskip H, Barraclough B. *Causes of the excess mortality of schizophrenia*. Br J Psychiatry 2000 Sep: 177: 212-7

<sup>62</sup> Dalack GW, Meador-Woodruff JH. *Smoking, smoking withdrawal and schizophrenia: case reports and a review of the literature*. Schizophr Res 1996 Nov 15: 22(2): 133-41

<sup>63</sup> Thornicroft G. *Shunned: Discrimination against People with Mental Illness*. Oxford: Oxford University Press: 2006

<sup>64</sup> Oud MJ, Meyboom-de JB. *Somatic diseases in patients with schizophrenia in general practice: their prevalence and health care*. BMC Fam Pract 2009; 10:32

<sup>65</sup> Fleischhacker WW, Cetkovich-Bakmas M, De HM, Hennekens CH, Lambert M, Leucht S, et al. *Comorbid somatic illnesses in patients with severe mental disorders: clinical, policy, and research challenges*. J Clin Psychiatry 2008 Apr: 69(4): 514-9

<sup>66</sup> Bouras N, Holt G. *Mental health services for adults with learning disabilities*. Br J Psychiatry 2004 Apr: 184: 291-2

<sup>67</sup> Patel V, Araya R, Chatterjee S, Chisholm D, Cohen A, De SM et al. *Treatment and prevention of mental disorders in low-income and middle-income countries*. Lancet 2007 Sep 15: 370(9591): 991-1005

### 3.4 Excess rates of co-morbidity and mortality

There are increased mortality rates among people with mental health disabilities or intellectual disabilities which are particularly related to higher rates of suicide, accidental or violent death (unnatural causes), and serious physical illnesses, as well as relative neglect within hospital and social care institutions<sup>68</sup>.

The combined effect of greater exposure to risk factors, contributes to excess rates of mortality for natural causes and of a substantially higher prevalence of physical co-morbidity among people with mental health disabilities and intellectual disabilities compared with the general population<sup>69,70</sup>. The more serious conditions are cardiovascular, respiratory, nutritional, metabolic, endocrine and epileptic disorders<sup>71</sup>. A proportion of such deaths (both for unnatural and natural causes) may be, and should be, avoidable. Many people in mental institutions in Europe, for example, have a diagnosis of schizophrenia. Only 80% of people with schizophrenia die from natural causes, compared with 97 per cent of the general population<sup>72,73</sup>, and the higher rates of unnatural deaths are largely attributable to accidents and suicide, which tend to occur more often in early than late adulthood<sup>74,75</sup>. In a recent Scandinavian study, the death rates from all external causes are quite high for people with schizophrenia<sup>76</sup>.

People with mental health disabilities and intellectual disabilities are more likely to experience particular types of physical illness in the following categories<sup>77</sup> and so these types of condition need to be routinely considered in monitoring and assessment of general health care:

- Respiratory disorders: chronic respiratory problems are more common among these particular groups<sup>78</sup>.
- Cardiovascular disease: people with severe mental health disabilities and intellectual disabilities die more frequently from cardiovascular diseases and experience sudden death more often than control populations<sup>79</sup>.
- Nutritional, metabolic and endocrine diseases: the most severe problems are obesity and diabetes associated with the use of antipsychotic medications, both of which in turn contribute to higher rates of cardio-vascular disease<sup>80</sup>. The metabolic syndrome also has higher rates in individuals with severe mental health disabilities and intellectual disabilities than in the general population<sup>81</sup>.
- Cancers: people with mental health disabilities and intellectual disabilities are also associated with disparities in screening for cancer and with higher case fatality rates. This is partly due to the particular treatment challenges when treating these patients including medical co-morbidity, drug interactions, lack of capacity and difficulties in coping with the treatment as a result of psychiatric symptoms<sup>82,83,84</sup>.

<sup>68</sup> Amaddeo F, Barbui C, Perini G, Biggeri A, Tansella M. *Avoidable mortality of psychiatric patients in an area with a community-based system of mental health care*. Acta Psychiatr Scand 2007 Apr: 115(4): 320-5

<sup>69</sup> Harris EC, Barraclough B. *Excess mortality of mental disorder*. British Journal of Psychiatry 1998 Jul: 173: 11-53

<sup>70</sup> Sartorius N. *Physical illness in people with mental disorders*. World Psychiatry 2007 Feb: 6(1): 3-4

<sup>71</sup> Leucht S, Burkard T, Henderson J, Maj M, Sartorius N. *Physical illness and schizophrenia: a review of the literature*. Acta Psychiatr Scand 2007 Nov: 116(5): 317-33

<sup>72</sup> Goff DC, Cather C, Evins AE, Henderson DC, Freudenreich O, Copeland PM, et al. *Medical morbidity and mortality in schizophrenia: guidelines for psychiatrists*. J Clin Psychiatry 2005 Feb: 66(2): 183-94

<sup>73</sup> Llorca PM. *Monitoring patients to improve physical health and treatment outcome*. Eur Neuropsychopharmacol 2008 Aug: 18 Suppl 3: S140-S145

<sup>74</sup> Brown S, Inskip H, Barraclough B. *Causes of the excess mortality of schizophrenia*. Br J Psychiatry 2000 Sep: 177: 212-7

<sup>75</sup> Brown S, Kim M, Mitchell C, Inskip H. *Twenty-five year mortality of a community cohort with schizophrenia*. Br J Psychiatry 2010 Feb: 196(2): 116-21

<sup>76</sup> Tiihonen J, Lonnqvist J, Wahlbeck K, Klaukka T, Niskanen L, Tanskanen A, et al. *11-year follow-up of mortality in patients with schizophrenia: a population-based cohort study (FIN11 study)*. Lancet 2009 Aug 22: 374(9690): 620-7

<sup>77</sup> Leucht S, Burkard T, Henderson J, Maj M, Sartorius N. *Physical illness and schizophrenia: a review of the literature*. Acta Psychiatr Scand 2007 Nov: 116(5): 317-33

<sup>78</sup> Brown S, Kim M, Mitchell C, Inskip H. *Twenty-five year mortality of a community cohort with schizophrenia*. Br J Psychiatry 2010 Feb: 196(2): 116-21

<sup>79</sup> Correll CU. *Elevated cardiovascular risk in patients with bipolar disorder: when does it start and where does it lead?* J Clin Psychiatry 2008 Dec: 69(12): 1948-52

<sup>80</sup> Cohen D, Correll CU. *Second-generation antipsychotic-associated diabetes mellitus and diabetic ketoacidosis: mechanisms, predictors, and screening need*. J Clin Psychiatry 2009 May: 70(5):765-6

<sup>81</sup> Newcomer JW. *Metabolic syndrome and mental illness*. Am J Manag Care 2007 Nov: 13(7 Suppl): S170-S177.82

<sup>82</sup> Tran E, Rouillon F, Loze JY, Casadebaig F, Philippe A, Vitry F et al. *Cancer mortality in patients with schizophrenia: an 11-year prospective cohort study*. Cancer 2009 Aug 1: 115(15): 3555-62

<sup>83</sup> Howard L, Barley E, Davies E, Lempp H, Rose DS, Thornicroft G. *A diagnosis of cancer in people with severe mental illness: practical and ethical issues raised*. Lancet Oncology 2010: In press

<sup>84</sup> Catts VS, Catts SV, O'Toole BI, Frost AD. *Cancer incidence in patients with schizophrenia and their first-degree relatives - a meta-analysis*. Acta Psychiatr Scand 2008 May;117(5):323-36

■ Musculo-skeletal disorders: higher rates of bone mineral density (osteoporosis) have been found among people with schizophrenia, along with less appropriate treatment<sup>85</sup>.

■ Dental problems: higher rates of dental decay and tooth loss have been reported among people with mental health disabilities and intellectual disabilities, indicating the importance of special attention to dental problems<sup>86,87</sup>.

■ Neurological disorders: the most serious long-term extra-pyramidal side-effect of first generation antipsychotic medications is tardive dyskinesia, while other abnormal motor symptoms such as akathisia) are also commonly caused by antipsychotic medications<sup>88</sup>.

■ Obstetric complications: there is an extensive literature that demonstrates increased occurrence of obstetric complications among mothers with schizophrenia, which may be associated with high rates of smoking, the use of illicit drugs and alcohol and the intake of antipsychotic medication<sup>89</sup>.

■ Hepatitis: an increased prevalence of hepatitis in people with schizophrenia compared to the general population has been reported in many countries including Jordan, India, US, Italy, Turkey and Japan<sup>90</sup>.

■ HIV/AIDS: higher rates may reflect the frequency of substance abuse, sexual risk behaviours and a reduced knowledge about HIV-related issues<sup>91</sup>.

### 3.5 Learning/intellectual disabilities and general health care

In addition to the issues described in the preceding sections, people with intellectual disabilities are also at higher risk for further specific difficulties which need to be assessed and addressed in any full assessment of general health care<sup>92</sup>. These particular issues include challenging behaviour<sup>93,94</sup>, the need for special educational assistance<sup>95</sup>, higher rates of forms of epilepsy<sup>96</sup>. Additional issues that merit regular assessment are dental problems, cardio-vascular abnormalities, spinal deformities and visual and hearing impairments<sup>97,98</sup>.

### 3.6 Stigma, discrimination and 'diagnostic overshadowing'

There is strong evidence that people with mental health disabilities and intellectual disabilities receive worse treatment for physical disorders. One of the factors contributing to this is 'diagnostic overshadowing'. This is defined as the process by which people with mental health disabilities and intellectual disabilities receive poorer physical health care because general health care staff are poorly informed or mis-attribute physical symptoms to mental health disabilities and intellectual disabilities. It has been best investigated in people with learning disabilities and in medical settings<sup>99,100</sup>.

<sup>85</sup> Levine J, Belmaker RH. *Osteoporosis and schizophrenia*. Am J Psychiatry 2006 Mar: 163(3): 549-50

<sup>86</sup> Gabre P. *Studies on oral health in mentally retarded adults*. Swed Dent J Suppl 2000: (142): 1-48

<sup>87</sup> McCreddie RG, Stevens H, Henderson J, Hall D, McCaul R, Filik R, et al. *The dental health of people with schizophrenia*. Acta Psychiatr Scand 2004 Oct: 110(4): 306-10

<sup>88</sup> Correll CU, Leucht S, Kane JM. *Lower risk for tardive dyskinesia associated with second-generation antipsychotics: a systematic review of 1-year studies*. Am J Psychiatry 2004 Mar: 161(3): 414-25

<sup>89</sup> Howard LM, Thornicroft G, Salmon M, Appleby L. *Predictors of parenting outcome in women with psychotic disorders discharged from mother and baby units*. Acta Psychiatr Scand 2004 Nov: 110(5): 347-55

<sup>90</sup> Rosenberg SD, Goodman LA, Osher FC, Swartz MS, Essock SM, Butterfield MI et al. *Prevalence of HIV, hepatitis B, and hepatitis C in people with severe mental illness*. Am J Public Health 2001 Jan: 91(1): 31-7

<sup>91</sup> Essock SM, Dowden S, Constantine NT, Katz L, Swartz MS, Meador KG et al. *Risk factors for HIV, hepatitis B, and hepatitis C among persons with severe mental illness*. Psychiatr Serv 2003 Jun: 54(6):836-41

<sup>92</sup> Bouras N. *Mental health and related issues for people with intellectual disability*. Curr Opin Psychiatry 2009 Sep: 22(5): 429-30

<sup>93</sup> Cooper SA, van der SR. *Epidemiology of mental ill health in adults with intellectual disabilities*. Curr Opin Psychiatry 2009 Sep: 22(5): 431-6

<sup>94</sup> Totsika V, Felce D, Kerr M, Hastings RP. *Behavior Problems, Psychiatric Symptoms, and Quality of Life for Older Adults With Intellectual Disability With and Without Autism*. J Autism Dev Disord 2010 Feb 25

<sup>95</sup> Kauffman JM, Hung LY. *Special education for intellectual disability: current trends and perspectives*. Curr Opin Psychiatry 2009 Sep: 22(5): 452-6

<sup>96</sup> Kerr M, Scheepers M, Arvio M, Beavis J, Brandt C, Brown S et al. *Consensus guidelines into the management of epilepsy in adults with an intellectual disability*. J Intellect Disabil Res 2009 Aug: 53(8): 687-94

<sup>97</sup> Bouras N, Holt G. *Mental health services for adults with learning disabilities*. Br J Psychiatry 2004 Apr: 184: 291-2

<sup>98</sup> Pradhan A, Slade GD, Spencer AJ. *Access to dental care among adults with physical and intellectual disabilities: residence factors*. Aust Dent J 2009 Sep: 54(3): 204-11

<sup>99</sup> Disability Rights Commission. *Formal Investigation Report Part 1: Equal Treatment: Closing the Gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems*. DRC: London, 2006a. Available at: [http://83.137.212.42/sitearchive/DRC/PDF/mainreportpdf\\_healthFIpart1.pdf](http://83.137.212.42/sitearchive/DRC/PDF/mainreportpdf_healthFIpart1.pdf)

<sup>100</sup> Disability Rights Commission. *Formal Investigation Report Part 2: Report of the DRC Formal Inquiry Panel to the DRC's Formal Investigation. The inequalities in physical health experienced by people with mental health problems and people with learning disabilities*. DRC: London, 2006b. Available at: [http://83.137.212.42/sitearchive/DRC/PDF/inquiry\\_panel.pdf](http://83.137.212.42/sitearchive/DRC/PDF/inquiry_panel.pdf)

This concept has been explored in the literature on people with intellectual disabilities for over two decades, but it is an area that has received very little attention in the mental health literature, although mental health service users have extensively reported the occurrence of this phenomenon<sup>101</sup>. One of the implications of such discrimination and neglect are higher mortality rates among people with mental health disabilities and intellectual disabilities for deaths by cardiac infarctions<sup>102,103</sup>. For example, after adjusting for other risk factors, such as cardiovascular risk factors and socio-economic status, depression in men was found to be associated with an increase in cardiovascular-related mortality<sup>104</sup>.

The reasons for this health care disparity is not well understood. One major associated factor is the stigmatising approaches of physicians and other health care staff, which reveal negative stereotypes<sup>105</sup>. However, more recent studies suggest that another important factor may be that clinicians make different diagnostic and treatment decisions in relation to people with mental illness. 'Treatment overshadowing' is a term, which has been proposed to describe possible biases in actual treatment decisions. For example, this may include a clinician deciding against certain treatment because of an assumption that a person's mental illness precludes such intervention. It has been shown, for example, that people with co-morbid mental disorders were 'substantially less likely to undergo coronary re-vascularisation procedures' than those without mental disorders<sup>106</sup>. Similarly, people with co-morbid mental illness and diabetes who presented to an emergency department, were less likely to be admitted to hospital for diabetic complications than those with no mental illness<sup>107</sup>.

It is also clear that many health care professionals are not sufficiently trained to recognise and treat people with mental health and/or intellectual disabilities and to recognise the many interactions between physical and mental health problems. For example, a toothache can present as 'challenging

behaviour' in a person with limited communication skills. Further, social factors such as bereavement and other losses, or changes in social structure like moving from one home to another, incompatibility with other residents, disrespectful handling from carers, environmental causes like noise, or disruption of routine, can also manifest as 'challenging behaviour'. The use of medication in these cases is not only contraindicated, but can be adding to the distress already experienced. 'Treatment' for such situations is often simply achieved by manipulating the environment – ie removing the stress-inducing situation for the individual.

While conducting monitoring visits, the monitors should therefore keep the concept of diagnostic overshadowing clearly in mind. This is achieved by assessing the degree to which residents perceive that their health care needs are being met, whether they are being listened to and taken seriously when they complain of a physical health problem, and whether there is evidence from any source that their complaints regarding physical health problems are dismissed as 'part of their mental illness'. Monitors can ask these types of questions of staff and residents and attempt to understand the process of how physical health problems are handled in that particular setting. Of course, monitors cannot simply ask: 'Do you diagnostic overshadow?' This needs to be evaluated on the basis of all the observations and interviews with residents and staff, as well as any relevant documentation. A person on the monitoring team who is familiar with medical records could examine the records of several residents/interviewees to match the reported health conditions from some residents with the medical records. Discrepancies between what is reported and what is recorded could be an indication that diagnostic overshadowing is occurring in that context.

<sup>101</sup> Jones S, Howard L, Thornicroft G. 'Diagnostic overshadowing': worse physical health care for people with mental illness. *Acta Psychiatr Scand* 2008 Sep; 118(3): 169-71

<sup>102</sup> Desai MM, Rosenheck RA, Druss BG, Perlin JB. *Mental disorders and quality of care among postacute myocardial infarction outpatients*. *J Nerv Ment Dis* 2002 Jan; 190(1): 51-3

<sup>103</sup> Enger C, Weatherby L, Reynolds RF, Glasser DB, Walker AM. *Serious cardiovascular events and mortality among patients with schizophrenia*. *J Nerv Ment Dis* 2004 Jan; 192(1): 19-27

<sup>104</sup> Gump BB, Matthews KA, Eberly LE et al (2005). *Depressive symptoms and mortality in men: results from the Multiple Risk Factor Intervention Trial*. *Stroke*, 36, 98-102

<sup>105</sup> Filipic I, Pavicic D, Filipic A, Hotujac L, Begic D, Grubisin J et al. *Attitudes of medical staff towards the psychiatric label 'schizophrenic patient' tested by an anti-stigma questionnaire*. *Coll Antropol* 2003 Jun; 27(1): 301-7

<sup>106</sup> Druss BG, Bradford DW, Rosenheck RA, Radford MJ, Krumholz HM. *Mental disorders and use of cardiovascular procedures after myocardial infarction*. *JAMA* 2000 Jan 26; 283(4): 506-11

<sup>107</sup> Sullivan G, Han X, Moore S, Kotrla K. *Disparities in hospitalisation for diabetes among persons with and without co-occurring mental disorders*. *Psychiatric Services* 2006; 57: 1126-31

### 3.7 Access to mental health care

One of the consequences of stigma and discrimination is that people with mental health problems commonly avoid seeking help for their problems, often for fear of receiving a mental health related diagnosis<sup>108</sup>. It is only relatively recently that the full potency of such barriers to finding treatment and care have been recognised<sup>109, 110</sup>. For example studies from several countries have consistently found that even after a family member has developed clear-cut signs of a psychotic mental health problem, on average it is over a year until the unwell person first receives assessment and treatment<sup>111</sup>. A survey of almost 10,000 adults in 17 countries has added more detail to this picture. The results showed that the majority of people with mental disorders eventually contact treatment services, but they often wait a long time before doing so, with average delays before seeking help of 8 years for mood disorders, and at least 9 years for anxiety disorders. People who wait longer than average before receiving care are more likely to be young, old, male, poorly educated, or a member of a racial/ethnic minority<sup>112</sup>. At the policy level, the HealthQuest report by EU DG EMPLOY refers to access to general health care for people with mental disorders<sup>113</sup>.

The following common beliefs are likely to reduce their likelihood of seeking help: that psychiatric treatments are ineffective<sup>114</sup>; that others would react with avoidance; or that a person should solve their own problems<sup>115</sup>. At the same time strong family encouragement to go for mental health assessment and treatment does often work<sup>116</sup>.

It is fair to include not only individual but also systemic factors in trying to understand the puzzle of under-treatment. Such under-treatment is associated with patient, provider, and health care system factors<sup>117</sup>. Patient-based reasons include failure to recognise the symptoms, underestimating the severity, limited access, reluctance to see a mental health care specialist due to stigma, noncompliance with treatment, and lack of health insurance. Provider factors include poor professional school education about depression, limited training in interpersonal skills, stigma, inadequate time to evaluate and treat depression, failure to consider psychotherapeutic approaches, and prescription of inadequate doses of antidepressant medication for inadequate durations. Mental health care systems create barriers to receiving optimal treatment. It is especially important in institutions for people with mental health disabilities and intellectual disabilities to assess how far there is reasonable access to physical health care, with demonstrated parity to the levels of access available to people without mental health problems<sup>118,119</sup>. See Sections 8 and 9, Part 17, Access to physical health care, Part 18 Access to mental health services, Part 19 Access to general practitioners/family physicians, Part 20, Access to nurses and care staff and Part 21 Access to therapies.

<sup>108</sup> Thornicroft G, Brohan E, Rose D, Sartorius N, Leese M. *Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey*. *Lancet* 2009 Jan 20; 373: 408-15

<sup>109</sup> Amadeo F, Jones J. *What is the impact of socio-economic inequalities on the use of mental health services?* *Epidemiol Psychiatr Soc* 2007 Jan; 16(1): 16-9

<sup>110</sup> Cooper AE, Corrigan PW, Watson AC. *Mental illness stigma and care seeking*. *J Nerv Ment Dis* 2003 May; 191(5): 339-41.

<sup>111</sup> Compton MT, Kaslow NJ, Walker EF (2004). *Observations on parent/family factors that may influence the duration of untreated psychosis among African American first-episode schizophrenia-spectrum patients*. *Schizophr Res* 68 (2-3): 373-385

<sup>112</sup> Wang PS, Guilar-Gaxiola S, Alonso J, Angermeyer MC, Borges G, Bromet EJ, Bruffaerts R, de GG, de GR, Gureje O, Haro JM, Karam EG, Kessler RC, Kovess V, Lane MC, Lee S, Levinson D, Ono Y, Petukhova M, Posada-Villa J, Seedat S, Wells JE (2007). *Use of mental health services for anxiety, mood and substance disorders in 17 countries in the WHO world mental health surveys*. *Lancet* 370(9590): 841-850

<sup>113</sup> [http://ec.europa.eu/employment\\_social/spsi/docs/social\\_inclusion/2008/healthquest\\_en.pdf](http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/healthquest_en.pdf)

<sup>114</sup> Corrigan PW (2004). *On the Stigma of Mental Illness: Practical Strategies for Research and Social Change*. American Psychological Association: Washington DC

<sup>115</sup> Kessler RC, Berglund PA, Bruce ML, Koch JR, Laska EM, Leaf PJ, Manderscheid RW, Rosenheck RA, Walters EE, Wang PS (2001). *The prevalence and correlates of untreated serious mental illness*. *Health Serv Res* 36 (6 Pt 1): 987-1007

<sup>116</sup> Link BG, Cullen FT, Struening EL, Shrout PE, Dohrenwend BP (1989). *A modified labeling theory approach in the area of mental disorders: An empirical assessment*. *American Sociological Review* 54: 100-123

<sup>117</sup> Simon GE, Fleck M, Lucas R, Bushnell DM. *Prevalence and predictors of depression treatment in an international primary care study*. *Am J Psychiatry* 2004; 161(9): 1626-1634

<sup>118</sup> Hirschfeld RM, Keller MB, Panico S, Arons BS, Barlow D, Davidoff F, Endicott J, Froom J, Goldstein M, Gorman JM, Marek RG, Maurer TA, Meyer R, Phillips K, Ross J, Schwenk TL, Sharfstein SS, Thase ME, Wyatt RJ (1997). *The National Depressive and Manic-Depressive Association consensus statement on the undertreatment of depression*. *JAMA* 277(4): 333-340

<sup>119</sup> Castiello G, Magliano L (2007). *Beliefs about psychosocial consequences of schizophrenia and depression: a comparative study in a sample of secondary school students*. *Epidemiol Psychiatr Soc* 16 (2): 163-17

### 3.8 Vaccination and immunisation

An important aspect of comprehensive general health care is the full provision of routine and necessary vaccinations and immunisations<sup>120</sup>.

WHO has published standard guidelines on routine immunisations for children, adolescents, and adults<sup>121</sup>. Within institutions, monitors will need to establish whether routine vaccinations and immunisations are being administered on a proper basis (see Sections 8 and 9, Part 22, Health care records).

### 3.9 Monitoring the delivery of appropriate treatment and care

For the reasons described above, people in mental institutions require proper and regular assessments of their general health care<sup>122</sup>. One implication of this is that it is important to identify who is responsible for the physical health care of such groups of people, for, for example, at least annual physical health assessments for longer-term residents in institutions. Communication and collaboration with other medical staff is essential. Such regular checks are likely to need to include assessments for signs or symptoms of cardiovascular disease, hypertension, diabetes, obesity, height and weight, dental checks, visual and auditory tests, and the provision of health screening procedures recommended for the general population.

More specifically, monitors may need to assess, where appropriate, the provision of routine physical investigations such as physical examination, investigations such as blood and urine test, blood sugar or cholesterol levels, ECG/EKG, and chest X-rays) performed at regular intervals, with appropriate informed consent, mammogram, pap-tests, faecal (stool) blood tests, colonoscopy, urine tests, skin and mouth examination, along with assessments of incontinence, pulse rate, respiratory rate, temperature, or bedsores (for residents spending long periods in bed). Monitors will need to assess whether a satisfactory record exists of a full health care assessment for the resident on admission to the institution (Sections 8 and 9, Part 25).

Following a full assessment of the nature of the mental health disorder, intellectual disability or physical health problems, it is usual for the appropriate health care staff to make and record a clear diagnosis of the conditions identified as the basis for deciding treatment within the care plan. Monitors should assess whether a clear statement of such diagnoses is given in the case records (see Sections 8 and 9, Part 26).

Regarding access to the provision of general health care, the main issue is whether residents have access to these services, not whether they are provided in the institution. In line with the CPRD paradigm, social inclusion is the aim. Thus, general health services to disabled people should be provided within the local community. By building 'full service' institutions we actually may foster social exclusion instead of social inclusion. Nevertheless, where such services are provided within institutions, then the following issues may be addressed: is proper equipment available or accessible, eg appropriate clinical rooms, examination couches, blood pressure equipment, weighing scales and other necessary equipment? Are the required arrangements in place for relevant immunisations and vaccinations? Are the full range of health screening procedures made available to the general population also equally provided for the residents of the institution? (see Section 8 and 9, Part 24).

Electro-convulsive treatment (ECT) is a controversial treatment and has raised concerns for its sometimes serious side effects, including fractures (before the use of neuromuscular blocking agents) and cognitive (memory) impairment<sup>123,124,125</sup>. Monitors may therefore need to establish whether and how ECT is used in the institution being assessed, for example by inquiring about the use of consent, anaesthetic sedation, resuscitation equipment, and the administration of ECT in accordance with relevant protocols (see Sections 8 and 9, Part 27).

<sup>120</sup> Bazelon DL (2004). *Get it together: How to integrate physical and mental health care for people with serious mental disorders*. Washington DC

<sup>121</sup> [www.who.int/immunization/policy/Immunization\\_routine\\_table1.pdf](http://www.who.int/immunization/policy/Immunization_routine_table1.pdf)  
[www.who.int/immunization/policy/Immunization\\_routine\\_table2.pdf](http://www.who.int/immunization/policy/Immunization_routine_table2.pdf)  
[www.who.int/immunization/policy/immunization\\_tables/en/index.html](http://www.who.int/immunization/policy/immunization_tables/en/index.html)

<sup>122</sup> Llorca PM. *Monitoring patients to improve physical health and treatment outcome*. *Eur Neuropsychopharmacol* 2008 Aug;18 Suppl 3:S140-S145

<sup>123</sup> Leucht S, Corves C, Arbter D, Engel RR, Li C, Davis JM. *Second-generation versus first-generation antipsychotic drugs for schizophrenia: a meta-analysis*. *Lancet* 2009 Jan 3; 373(9657): 31-41

<sup>124</sup> Rose D, Fleischmann P, Wykes T, Leese M, Bindman J. *Patients' perspectives on electroconvulsive therapy: systematic review*. *BMJ* 2003 Jun 21; 326(7403): 1363

<sup>125</sup> Carney S, Geddes J. *Electroconvulsive therapy*. *BMJ* 2003 Jun 21;326(7403):1343-4

### 3.10 Latrogenic risks of prescribed medication

A further set of important risk factors are the side effects of prescribed medication. Many types of antipsychotic medication can cause significant weight gain, metabolic syndrome, diabetes mellitus and cardiovascular disorders. Even so, a recent study from Finland found that over a 10 year period the mortality gap between the general population and people with schizophrenia in fact decreased from 25 years to 22.5 years<sup>126</sup>.

For all of these reasons, regular and comprehensive assessments of the physical health of people with mental health disabilities and intellectual disabilities are required, along with proper treatment of any conditions detected. Section 8 and 9, Part 22 (Health care records) will be one important source in monitoring the detection of such side effects of medication.

### 3.11 Participation in health care decision-making

Service user involvement in the planning and provision of mental health services has been growing over the last two decades in many countries, especially in areas where institutional service provision has been changed to a community-orientated model of care<sup>127,128</sup>. Service user involvement in the process of care may directly contribute to better outcomes of treatment, for example through better treatment adherence<sup>129</sup>. This Toolkit therefore assesses the nature of participation in health care decision-making by residents in mental institutions. Section 8, part 22 (health records) will be one important source to assess if there is any documented evidence of consumer participation in healthcare related decision-making. Section 8, part 29 of the Toolkit allows monitors to record what information is available on how far residents participate in such decision-making. One specific form of participation refers to involvement in research. While exact regulations and provisions differ between countries, there is usually a minimum requirement that any such participation requires the written, informed consent of residents, with a clear undertaking that non-participation will lead to no detriment in their quality of treatment or care (see Sections 8 and 9, Part 30).

<sup>126</sup> Tiihonen J, Lonnqvist J, Wahlbeck K, Klaukka T, Niskanen L, Tanskanen A et al. *11-year follow-up of mortality in patients with schizophrenia: a population-based cohort study (FIN11 study)*. *Lancet* 2009 Aug 22; 374(9690): 620-7.

<sup>127</sup> Chamberlin J. User/consumer involvement in mental health service delivery. *Epidemiologica e Psichiatria Sociale* 2005;14(1):10-4

<sup>128</sup> Sweeney A, Beresford P, Faulkner A, Nettle M, Rose D, (eds). *This Is Survivor Research*. Ross-on-Wye: PCCS Books; 2009.

<sup>129</sup> Rose D, Lucas J. *The User and Survivor Movement in Europe*, in Knapp M, McDaid D, Mossialos E, Thornicroft G, (editors) *Mental Health Policy and Practice Across Europe. The Future Direction of Mental Health Care*. Milton Keynes: Open University Press; 2006

## Section 4 **Why do human rights monitoring?**

In Section 2 of the Toolkit, we introduced the concept of human rights, and set out a range of instruments, particularly the UN Convention on the Rights of Persons with Disabilities (CRPD). Section 4 flows from this in setting out the issues which are dealt with in the prompt questions (Section 9) and setting out how they refer to the CRPD. This Section of the Toolkit turns to the practicalities of carrying out human rights monitoring in mental health and social care institutions. It first looks at the purpose of human rights monitoring, which include advocacy and campaigning, awareness-raising, capacity-building, motivating others to participate in monitoring, and raising an organisation's profile, and how human rights monitoring can feed into the process of litigation.

As discussed in Section 2.3 above, the CRPD envisions a paradigm shift towards viewing people with disabilities as subject-holders of human rights, rather than objects of treatment and management. The paradigm shift involves more than simply ratifying the Convention and carrying out domestic law reform. To be meaningful, the paradigm shift needs to include challenging, changing or abolishing many long-held and entrenched attitudes, behaviours and practices. This means that services have to be established or altered, and people need to be re-skilled. To ensure this happens, a continuous quality improvement process which involves evaluation and adjustments needs to be put in place. An incremental approach needs consistency and time. As the Nobel prize-winning physicist Max Planck once observed, 'a new scientific truth does not triumph by convincing its opponents and making them see the light, but rather because its opponents eventually die, and a new generation grows up that is familiar with it'.

Within a process of interlocking stages and points of interaction, monitoring human rights observes reality at one specific point in time. For this reason, questions which monitors ask during a monitoring visit must be formulated in a manner that can be answered at that time. At a later date, it may be that the same questions need to be asked. If there have been significant changes, a different set of questions might need to be asked. In both cases, comparisons over time can be made.

In order to properly assess the situation across time, monitors must both cover the ground by asking the key questions, and calibrate questions in light of the State's legal system, and of the stage of development of mental health and social care services. As an example, when monitoring an institution, questions will need to be

asked to find out whether a State is transforming its laws from a model of substituted decision-making or guardianship towards supported decision-making. Monitors could ask: 'How many, and what percentage of the residents, are under guardianship?' This question serves as a source of statistical information about guardianship, and as an entry point into related topics such as conflict of interest, consent to treatment, and confidentiality. On a subsequent monitoring visit, the monitor may know that there are fewer people in the State under guardianship, but the same question should be asked so that direct comparisons can be made over time. This example illustrates the importance of gathering credible evidence of the current reality, and the importance of monitors being well-prepared for a monitoring visit by knowing the relevant laws and the state of their implementation (see Section 7, Step 5, Plan the visits).

Documented reality can be compared not only across time, but also against domestic laws and policies, and against international standards such as the CRPD. It is only when the reality is monitored against a set of standards that monitors can assess whether international and domestic laws and policies are being implemented. Monitoring human rights is a key method of ensuring the implementation of international and domestic legal standards.

Human rights theory itself deals with the fact that human rights are (or are not) respected within dynamic and shifting social settings. The concept of progressive realisation of human rights means that States should take steps to respect, protect and fulfil those rights which are more resource-dependent than others. Progressive realisation means that States must gradually implement a right by taking all appropriate means, including legislative and administrative measures, to the maximum of its available resources. The notion of progressive realisation applies generally to economic and social rights, such as the rights to education, health and employment. Inherent within the principle of progressive realisation is the principle of non-regression, which means that a State should not undo norms already in existence: States must always provide more human rights protection, not less. Some rights, such as the obligation on States to ensure enjoyment of all rights without discrimination, are rights of immediate obligation.

States must fulfil their obligations to implement the right of people with disabilities to live in the community<sup>130</sup>. Whilst this obligation remains

<sup>130</sup> See article 19 of the UN Convention on the Rights of Persons with Disabilities

unfulfilled, States must ensure that when inside institutions, people's human rights are fully respected and protected. They must also ensure that human rights are protected in institutions that are based in general hospitals and within communities. The respect and protection of human rights cannot be assured unless and until the cloak of invisibility, so common to institutions, is lifted. The most effective way of removing this cloak is through the active use of independent inspectorates because without them, neglect and abuse will continue with impunity, and will continue to be unnoticed and unremedied.

The imperative of monitoring mechanisms in the protection of human rights is recognised in international human rights texts. More specifically, States party to certain international instruments, which include the CRPD, are obliged to establish national mechanisms to monitor human rights of all people within their jurisdiction wherever they live. Nonetheless, even amongst those countries which do provide for national inspectorate mechanisms, there remain many mental health and social care institutions that continue to avoid meaningful scrutiny.

As noted in Section 2, at the international level, the Optional Protocol to the United Nations Convention against Torture (OPCAT) specifically requires States to establish independent inspectorates, referred to as 'national preventive mechanisms', for all places of detention. Monitoring also happens by international bodies such as the UN's Subcommittee for the Prevention of Torture (SPT) and the Council of Europe's Committee for the Prevention of Torture (CPT). The CPT, which was 20 years old in 2009, has visited many mental health and social care institutions, and visits have led to both concern being expressed at the gap in protection for those within the institutions, and an exhortation for the establishment – with full State support – of independent national inspectorates. Indeed the CPT has developed specific standards regarding 'involuntary placement in psychiatric institutions' (8th General Report on activities, 1998<sup>131</sup>) as well as regarding 'means of restraint in psychiatric establishments for adults' (16th General Report on activities, 2006<sup>132</sup>).

This Toolkit is designed to assist inspectors to monitor human rights of mental health and social care institutions, and in that regard the main audiences are national human rights institutions, ombudsman offices, 'national preventive mechanisms' under OPCAT, independent non-governmental organisations – be they human rights organisations or disabled people's organisations. The Toolkit is aimed to rebalance the lack of attention paid, at the national level and at the

international level, to the human rights of those detained in institutions which house people with disabilities<sup>133</sup>.

Regular and independent monitoring of mental health and social care institutions can lead to improved human rights for people with disabilities. In addition, monitoring of these institutions can contribute to social changes in several ways. To a large extent the results of any monitoring visit will depend on who has conducted the monitoring, why the monitoring was conducted, the resources the monitoring team or organisation have at their disposal to influence forces of change, and whether the authorities are willing and able to make the necessary changes.

Where monitoring has been commissioned by government or has had the strong support of government, monitoring results can feed directly back to the decision-makers who may, as a result of the monitoring, make important changes to services. For example, following a report that finds that many of the residents in a particular institution are being unjustly kept in the institution without their consent, government may decide to redistribute funding currently used for institutionalisation, and instead earmark it for community-based services.

A report given directly to a director of an institution may result in changes that are easily implemented but which the institutional staff may not have been aware existed, or that such issues were matters of human rights. For example, the director may discipline a particular staff member responsible for verbally threatening detainees, or pass the case to the local police. A report may result in the institution allowing patients to wear their own clothes rather than institutional uniforms, or being able to read their letters without them being opened by staff first.

A monitoring report can be the catalyst for change at various levels. Having the government and even the institution itself supporting the monitoring and being committed to reviewing the results and the recommendations is an important part of ensuring better human rights for people in institutions. In other situations, however, a monitoring team which is perceived as being too closely aligned with government can obstruct the realisation of better human rights. Governments may restrict or embargo results being made public, they may attempt to influence the results or they may read the report but do nothing about it.

Once a report has been published, follow-through is essential. Whether follow-through is carried out by the inspectorate or other organisations will depend on the local circumstances and the mandate and scope of the inspectorate.

<sup>131/132</sup> 8th General Report on the CPT's activities covering the period 1 January to 31 December 1997, CPT/Inf (98) 12 [EN], Publication Date: 31 August 1998. 16th General Report on the CPT's activities covering the period 1 August 2005 to 31 July 2006, CPT/Inf 35, Publication date: 16 October 2006

<sup>133</sup> For more on the legal and structural reforms which States should implement to ensure effective inspectorate systems, see *Inspect!*, Mental Disability Advocacy Center, 2006, available from [www.mdac.info](http://www.mdac.info)

Follow-through activities may include the following:

- **Advocacy and campaigning**

Monitoring and documenting problems provides evidence that can be used to demonstrate a particular human rights situation. Governments and policy-makers are likely to respond to evidence-based advocacy. Without evidence, claims may be dismissed as unfounded and biased opinion. Evidence enables the status quo to be challenged. Evidence can also be sent to third parties (such as international organisations like relevant bodies of the United Nations, non-government organisations or influential individuals) to intervene, put pressure on governments and call for change. Evidence can also be used in small or large-scale public campaigns.

- **Awareness-raising**

It is often crucial to reach the public in order to garner support for changes. One important way of doing this is via the media: print, television, radio and online. Substantiated information can be used for media articles and features, and for public awareness campaigns. Raising the profile of the issue can help put pressure on governments and service providers to make changes. Media coverage equips members of the public with the knowledge to hold their elected officials to account and call for changes themselves.

- **Capacity-building**

Users of mental health and social care services themselves can utilise credible evidence on the human rights deficiencies in mental health and social care systems. It can help users of such services to frame their personal stories as human rights and legal issues, and demand increased respect, protection and fulfilment of their human rights. Personal abuses are often systematic failings. As well as possibly being 'empowering' for an individual, the evidence contained in a monitoring report can help people understand their rights, and demand them, either individually or jointly with others.

- **Influence and motivate others to participate in human rights monitoring**

A report which clearly sets out the problems may result in others becoming interested in taking up the issues. Such people and organisations may be from the human rights community (which in many countries often ignores the rights of people with disabilities) or people with mental health disabilities and intellectual disabilities in particular. Lawyers, judges, doctors and nurses all have prejudices, and a credible human rights report can influence them to be self-reflective and increase the attention they pay to the issues.

- **Raising an organisation's profile**

A credible human rights report can enable organisations (including national human rights institutions and ombudsman offices) to make informed decisions about strategic issues on which they should focus. Reports raise the likelihood of an organisation being consulted by government and other bodies, and may contribute to establishing the organisation as a key player. Credible reports contribute to a government taking seriously the views of such organisations in public policy-making, reviews and implementation. Collaborating with mental health service user organisations and NGOs of people with disabilities can have the knock-on advantage of raising their profile and contribute to combating stigma.

- **Litigation**

There are two ways that human rights monitoring reports can be used in legal cases. First, a report can demonstrate an issue and support an argument. Second, during human rights monitoring, the inspectors may well meet victims of human rights violations who are interested in using legal channels and becoming applicants for cases. The organisation conducting the monitoring can provide information about organisations and lawyers that may be able to help, and also comment on the extent to which detainees can access legal advice and assistance.

## Section 5 Principles of human rights monitoring

Human rights monitoring entails gathering accurate and reliable information. The process therefore needs to be thorough and fair. Sometimes this can be difficult because going into mental health or social care institutions is often an emotional experience. Furthermore, there is often limited time, issues are overwhelming, and there may be pressure to produce results. Bearing in mind these difficulties, it is important to plan in order to ensure that findings are credible, and to aim for the highest standard of accuracy possible within the circumstances. The principles outlined in this Section, or normative rules, represent standards any monitoring team should follow. Some of these principles have been derived from the 18 basic principles of monitoring identified in the United Nations Training Manual on Human Rights Monitoring<sup>134</sup>, which the authors of this Toolkit recommend as essential reading for anyone contemplating carrying out human rights monitoring of mental health or social care institutions. We suggest that these principles form a code of conduct, and should be kept in mind throughout the entire monitoring process.

### 5.1 Do no harm

Monitors must take every step to minimise risks to interviewees and detainees. In mental health and social care institutions, risks may include an interviewee facing retaliation or punishment for having spoken to a monitor. Such punishments may include seclusion, medication being increased, privileges being denied, or being given less food. Therefore, throughout discussions, and in the report, monitors should take care not to reveal identifying information. Thus, as well as not stating a person's name or initials, it may be best not to mention details about a person, even if they give their permission. For this reason, it is vital to interview several people, so that it is not obvious to the authorities who has said what. It can be a good idea to ask an interviewee if they think there are any risks for them, and monitors can leave their details so that if there are punishments following a monitoring visit, the monitors can react.

### 5.2 Carry out regular monitoring

Human rights monitoring implies regular or on-going monitoring in which there are repeated visits and regular and systematic follow-up to ensure improvements in human rights. Indeed, 'regular visits undertaken by independent [...] bodies to places where people are deprived of their liberty, in order to prevent torture and other cruel, inhuman or degrading treatment or punishment' is the very purpose of the OPCAT<sup>135</sup>.

### 5.3 Demonstrate independence

Independence and the appearance of independence are important for credible monitoring. Independence can mean different things, depending on the context.

#### ● Independence from the institutions

It is vital that the people or organisations carrying out human rights monitoring be independent from the institutions assessed. The OPCAT says that the functional independence of national inspectorate bodies should be guaranteed, as well as the independence of the individual staff<sup>136</sup>. Inspectorate bodies should ensure that their monitors are not part of and have no interest whatsoever in protecting any institution or people associated with any institution where monitoring takes place.

#### ● Independence from the government

Independence will guarantee that the government does not interfere in the process, or influence the results of monitoring, even if the government is funding the independent inspectorate body. States are encouraged to sign and ratify OPCAT. Once they have done so, they have a duty to establish and designate independent inspectorates to monitor places of detention. Under Article 33 of the CRPD, States have a duty to establish independent bodies to promote and protect the rights of persons with disabilities, and to monitor the implementation of the Convention. By definition, this means that the independent body will have to carry out regular visits to places of detention, especially in a country where there are no or inadequate monitoring bodies carrying out such visits.

<sup>134</sup> Chapter V of the *Training Manual on Human Rights Monitoring*, Professional Training Series n.7, Office of the High Commissioner for Human Rights, United Nations, New York, Geneva, 2001

<sup>135</sup> Optional Protocol to the UN Convention against Torture, Article 1

<sup>136</sup> Optional Protocol to the UN Convention against Torture, Article 18

In States where there are national human rights structures (national human rights institutions, ombudsman office or other formal and independent structures to promote and protect human rights), such bodies are often an excellent mechanism to conduct visits to places of detention. International and national non-governmental organisations concerned with human rights are also important and valuable players.

#### 5.4 Build a credible team

To be part of a monitoring team, it is not necessarily required to have qualifications (eg a university degree) or past experience (eg in evaluation of or in interviewing people with intellectual disabilities). It is, however, recommended that the monitors undergo specific training on the principles and methodology of monitoring, as well as the standards against which places of detention will be monitored.

Nevertheless, when selecting the members for a monitoring team, it is advised to build a multi-disciplinary team. Depending upon the purpose of the specific monitoring process, the members of the monitoring team may include:

- A person who is a user of mental health services or a former user of services. Ensuring that there is a person or more than one person with service user background will serve a number of advantages. It is likely that this person will be aware of issues which medics and lawyers without a service user background would simply miss. A service user can build up trust with patients/residents and yield information of a qualitatively richer nature. Recommendations which the monitoring team develop are likely to be more tailored to the needs of patients/residents if there is service user representation on the monitoring team. Article 33(3) of the CRPD says that any domestic monitoring of the implementation of the CRPD must involve persons with disabilities and their representative organisations.

- A health care practitioner with specific knowledge of mental health or intellectual disability. Having such a member as part of the monitoring team may make it easier to gain access to the institution. The clinician will be able to communicate directly with the staff on site, and may well be in an informed position to access and interpret medical and other healthcare information relevant for the human rights monitoring. Such professionals can take the lead in assessing the general health care elements of the human rights investigation.

- Someone with a background in human rights. Given that this is a human rights monitoring exercise, it is always useful to have an expert on human rights law, and preferably on mental health law, or intellectual disability law. It is useful to have a human rights defender who has experience of monitoring other types of place of detention (eg prisons, refugee centres, children's institutions and so on).

Inspectorates might want to bring in other individuals or organisations as experts, especially if those other individuals or organisations have greater experience of mental health disability services or of general human rights monitoring. NGOs or individuals can provide expert knowledge and often contacts too. In many countries, national monitoring mechanisms as well as human rights organisations lack specific expertise in monitoring the rights of people in mental health and social care institutions, and may welcome such collaborations.

#### 5.5 Collect reliable information

It is vital that monitors attempt to triangulate information, which simply means gathering information using a variety of sources. A monitor should not be dependant on just one person's opinion. Corroborating evidence is particularly important in this area of monitoring, as unfortunately it is often the case that statements given by people with mental health disabilities may not be taken seriously by others, and may be dismissed as coming from someone who is incompetent and does not know what they are talking about.

- Use primary (direct) sources. It is more convincing to hear about a problem from someone who is directly affected, than to hear about it from someone who heard about it from someone else.

- Be impartial. Monitors should say things which demonstrate to the staff and the detainees alike that the monitors base their analysis on the assessment rather than their personal views.

- Use fresh information. The older the information is the more likely it is to be inaccurate because of changes taking place. Furthermore, people's memories are at risk of fading, and therefore statements may be regarded as less credible

### **5.6 Adopt an inquisitive mindset**

Monitors should question and test the reliability of their information, sources and contacts. They should search for details by asking follow-up questions which go deeper into an issue. They should check out inconsistencies by asking the same question phrased differently, putting one piece of information to someone else and asking them to respond. It is vital that all members of the monitoring team are people who take a rigorous approach to understanding how a system is run in an institution, have sensitivity to a wide range of human rights issues, and have excellent talking skills. As soon as the monitoring team enters the institution, they should forget their professional background and concentrate on being investigators with all of their senses on high alert, fully switched on to what is happening around them.

### **5.7 Store information securely**

Monitors should ensure that the information collected, and records and notes that have been made during a visit, are kept in a safe place because they may be useful in the future. Monitors should note where information came from. This may involve recording a person's name and contact details (even though these are unlikely to be published in a report). This information should be kept in a secure place, to protect confidentiality. Other steps might involve sending encrypted files by emails with passwords being shared by telephone.

## Section 6 **Methods of human rights monitoring**

The greater variety of techniques employed, the greater the credibility of the resultant reports. In this Section, we outline three techniques for obtaining information: interviewing, observing and reviewing documentation. Then we discuss the possible ways you can record the collected information.

### 6.1 Method 1 Interviewing

Interviews are discussions, an exchange of words, a means to get information. In this sense, we do not mean formal tape-recorded interviews with structured questions and answers. Interviews can be carried out with patients/residents, staff members and visitors at an institution. Staff may include the director, psychiatrists, nurses, auxiliary staff, security guards, administrative staff, cooks, cleaners and gardeners. All of these people may be able to shed light on institutional issues.

Interviews can generate quotations which are also important in resultant reports of the monitoring visit. They show that people have been spoken to directly and that the report is about what people in the situation are actually saying (rather than reflecting just the monitors' opinions). They bring a report to life: rather than just containing factual information, the human impact of a situation can be shown.

#### ● Number and length of interviews

Monitors do not need to speak with as many people as possible, but simply with a representative sample of people. Sometimes, speaking with a handful of people garners 'enough' information. It is not necessary to discuss all issues with every interviewed individual. Allow for a natural flow in the conversations. Monitors need to remember that many institutions are people's homes and to be accordingly respectful and considerate. For example, wait to be invited in to personal areas, and do not touch people's possessions without permission. Staff members may at times try to act as an intermediary between the monitors and the residents, selecting residents for interviews, or giving monitors direct permission to talk to a resident without first consulting the resident. Especially in these cases, it is very important for monitors to address the individual directly, and ask for their explicit permission to engage in a discussion.

#### ● Location

Much of what is discussed will be personal and sensitive and may put the interviewee at risk, so it is essential to ensure confidentiality. Monitors should conduct interviews in a private and comfortable space. This is not always possible, but effort should be made to ensure that others are at least out of hearing and possibly out of sight. For example, a monitor could go for a walk in the grounds of an institution, or ask to talk to the person in his or her bedroom, if this is not too intrusive and the person agrees.

#### ● Anonymity and confidentiality

Any attributable information presented in the resultant monitoring report may attract retribution to the named individual. Therefore, monitors should weigh up the risks to a patient/resident even if consent to be named is given. An unforeseeable risk is that the interviewee may change his or her mind, and may not be able to contact the monitoring team later. There is an argument that it is not possible to give a real informed consent when living in an institution because patients/residents may be so used to agreeing with authority figures, including visitors like human rights monitors. It can be helpful to discuss what potential risks the patient/resident thinks there are for them, and if they think there is anything which monitors can do to minimise the risks. If monitors do choose to identify a patient/resident, monitors should explain to the person that if there is any intimidation or pressure, the monitoring body should be contacted as soon as possible. The authors of this Toolkit recommend that monitors do not name a patient/resident in resultant reports, because the risks of doing so can be high.

#### ● Selecting staff to interview

Monitors should enter an institution bearing in mind that it is likely that staff members care about what they do and are trying to do their best. Monitors should ask staff to provide information on a range of topics. Monitors can approach staff and as an opening question can ask them a general question like 'What problems do you face in your daily work? I'd like to find this out so that we can write a report to the institution and the government, and the report may be able to contribute to an improvement of the situation for you and the patients/residents you look after.' For staff on wards, monitors might open a casual conversation with 'How long have you worked here?', and then acknowledge that it must be difficult to work in the institution. It is surprising sometimes how far a little empathy goes.

In terms of types of staff, there are usually many different categories in an institution. These may include directors/managers, clinical staff, auxiliary staff, administrative staff, finance staff, security guards, kitchen staff and gardeners. They can all provide information about different things.

As for the professional staff, the director or deputy director will be able to provide statistics and data about the institution (see Parts 1 and 2 in Sections 8 and 9). They will give monitors the 'corporate' view of the institution, provide an overview of the main problems as they see them, as well as major incidents (fires, escapes, suicides etc) and how they were dealt with. They should also

be in a position to give policy answers to questions about how the institution deals with allegations of ill-treatment, how the institution deals with someone wanting to make a complaint and so on.

Finance staff may be able to give information about the budget received from governmental and other sources, and the percentage of the institutional budget spent on the usual categories: staff salaries, therapies (sometimes this is solely medication), food and running costs like heating, water and so on. There might be a separate budget for rehabilitation activities, depending on the type of institution. The finance staff might be able to say something about the financial constraints the institution is working under, and whether there is any funding for providing community mental health or social care services as an alternative to those provided in the institution.

Medical staff may include a clinical director, medical director, nursing director and so on. These people will be able to provide information about recruitment of healthcare staff, about their training, about shifts, about supplies of medications and how clinical staff deal with issues such as challenging behaviour.

More junior medical staff may have a better understanding of the problems on the ward/department and may want to share with you their anxieties about how the institution is managed. They may have more recent training than the senior medical staff and therefore may have more of a human rights approach. Monitors could ask them about general healthcare of their patients, including issues of screening and treatment for somatic conditions. They will be able to describe the quantity and quality of medications available. They will be able to shed light on areas of law in practice, such as what they do when a person is admitted to the hospital, what happens if someone gets pregnant, whether there is adequate medical cover for all patients/residents, and what happens when someone dies.

In addition to junior doctors, the institution may employ trained nurses, and these are the people who usually run hospital departments and know what the day-to-day problems are. There may be other healthcare professionals working in the institution such as psychologists,

social workers, occupational therapists, and speech and language therapists: they will all have their own perspective on the running of the institution in relation to human rights.

Auxiliary staff are those without any formal training, and these are usually badly-paid staff who may be happy to tell monitors their experience of how patients/residents are treated. They are usually the people who are called to restrain patients and monitors can ask them, for example, to demonstrate what happens when someone gets violent.

Security staff are useful sources of information about restraints, and about which patients/residents can leave the institution, as well as when and how they can do so.

In addition to the institutional staff, there may be other people in the institution at the time of the visit who can provide useful information, especially if they are regular visitors. These include lay (non-lawyer) advocates, attorneys, judges, religious leaders and so on.

#### ● Using interpreters

An interpreter may be needed when interviewing a resident from a linguistic minority, an asylum seeker or refugee, or when carrying out multi-country monitoring. If an interpreter is used, it is important that the interpreter has undergone checks to ensure that he or she is independent and not working for the institution being visited, or for governmental authorities. It is also vital to ensure that the interpreter is sensitive to the subject matter, understands the importance of confidentiality, will distinguish between what is said and what is their opinion, and will ask questions to interviewees in the manner and tone which the monitor asks them.

#### ● Selecting patients/residents to interview

When visiting an institution, several residents may rush up to monitors and seek their attention. It is possible to speak to these people to get information. Monitors should also seek out people who are quiet, who are sitting in a corner, who are not with the rest of the group. There are often reasons why someone is quiet or does not feel comfortable to be with a group of others.

In order to build up trust it is useful to have a general chat. This may involve 'hanging out', for example, just sitting and playing cards or having a drink. There can be an enormous pressure on interviewees because they may be aware that they only have limited time and opportunity to share their experiences. If they live in an institution, interviewees may feel anxious to suddenly have outsiders come and ask questions about their lives. In addition, some types of medication can make it difficult for people to concentrate for long. Talking about daily routine, mental health difficulties, and past events can be emotional. Monitors should be aware of and note the discomfort an interviewee may be feeling.

Interviewers can help interviewees feel at ease by explaining the purpose of the monitoring, showing they are listening carefully to all that is said, letting the interviewee speak in their own words as much as possible, showing that they understand that it is difficult, not passing judgement, not interrupting, allowing plenty of time, not getting irritated when things aren't going well, and by showing that they are genuinely interested in the interviewees' experiences and opinions. It can be helpful to show not just interest in factual information, but concern for how things are for the person. It may be a good idea to take breaks and to keep sessions short. It can be intimidating for some people to share information with a group of people, so some people may prefer talking on a one-to-one basis.

The first principle of human rights monitoring is to do no harm. It is important that the process of an interview is not damaging for the interviewee. Therefore, at all times, the wellbeing of the interviewee must be prioritised.

#### ● What to tell interviewees

Monitors should tell their name to the person they would like to speak to, their profession, explain where they are from and that they are not part of the institution. They should ask the person whether it would be OK to speak to them. If the person agrees, then it is a good idea to find a quiet place where staff cannot listen to the conversation.

Monitors should make clear that the information which is given will be treated confidentially. In psychiatric settings, monitors should tell the patients with whom interviews are being conducted that information will probably not help the person directly, rather that it will be used to form a picture of what is happening in the institution, so that the situation of people who come in the future might be better. In social care institutions, where residents stay a long time, the monitoring reports may actually result in changes which do positively affect the lives of the interviewees. Monitors cannot, however, promise such reforms.

The only reason why monitors would ever consider breaching confidentiality is if the patient/resident discloses that he or she is going to harm themselves or other people (see below, Dealing with actual harm and disclosures of harm).

● Ask open questions then seek detail  
Monitors should encourage patients/residents as well as staff to speak about the subjects that matter to them in their own words, as it will likely result in a richer testimony. Monitors should ask questions about the details of an event or situation and in doing so, should avoid leading questions. These are questions that suggest the answer in the question, thereby influencing or directing the person's answer. For example, asking 'Did that nurse beat you when you wanted more food?' is leading. Monitors should be aware that some persons with intellectual disabilities might be particularly suggestible, wanting to please the monitor by agreeing with them. Monitors should make a written note of the actual words spoken.

To find out what happened when the resident wanted more food, the monitor might ask: 'What happened next?' or 'How did the staff react?' Such questions enable the patient/resident to use their own words. Specific details are useful in helping human rights monitors understand and explain a situation. Generally, in the case of incidents or ongoing problems, the following questions can be helpful to get more information:

- What happened?
- To whom did it happen?
- When did it happen?
- How often did/does this happen?
- How were/are other people affected by it?
- How did/does it happen?
- Why did/does it happen?
- Was there any response by the staff?
- What has been done to prevent it happening again?

If a patient/resident is explaining something which happened, some useful questions to ask for more detail include:

- What happened then?
- Could you describe what it was like?
- Can you tell me a bit more about...?
- How did it make you feel?
- I've heard other people say [...] What do you think about this?
- What were, or are, the worst parts of all this?
- How would you like things to be done differently?

All of the above are 'open' questions where there are many possible answers. These are generally much more effective than 'closed' questions (where there are only 'yes' or 'no' answers).

### ● Weighing information

It is common to find inconsistencies whenever someone is telling their story. It would be easy to use such inconsistencies as a sign that the person giving the testimony is mentally incompetent in some way, therefore rendering their views and testimony as unreliable. Frequently, however, inconsistencies are a result of not understanding a question or answer, and/or not having enough information. Therefore it is worth re-phrasing questions in a different way, and asking directly about things which the monitor does not understand, or finds inconsistent.

In all settings, interviewees will inevitably come across as 'unreliable' for a variety of reasons. They may not want to talk to monitors, or they may be confused about events. For example, a person may be worried about what the staff of an institution will do to them if they speak to a monitor, and so may decide to just give the answers the staff would want. Even in these circumstances, or if someone is confused, some of what is said may still be useful.

For example, a person who speaks to some extent incoherently may also intersperse this with sentences about what their life is like in an institution. If an interviewee says something that does not make sense to the monitor, it can be helpful to remember that this may be very real for that person, even if it is part of a psychosis. Rather than regarding the person or their opinions as incorrect – as it is not based on the facts as known to the monitor at that time – it may be more helpful to regard these ideas as the experience and views of the person concerned which are different to the monitor's own experiences and views. Similarly, voices that a person hears may be very real to him/her, and impossible to distinguish from everyday voices that others hear. Voices are often an important part of somebody's life and what is said by the voices can be of significance. Likewise, visual hallucinations can feel real for the person experiencing them.

Generally, if monitors are not sure about anything, they should ask. Sometimes it is better to do this later, so the person is not interrupted when providing an information story. Checking out things which the monitor is not sure about can help to give interviewees confidence that the monitor is listening, and that monitors are accurate in their work. Monitors can also check out the reliability of an interviewee by asking questions to which monitors already know the answers.

Monitors should make a reasonable attempt to speak to enough patients/residents present in order to protect individuals from retribution, and in order to have a large enough sample to present credible evidence. In small institutions, it might be possible to speak with all the residents.

### ● Dealing with actual harm and disclosures of harm

Monitors may see physical signs of mistreatment, including injuries, difficulties of movement, or deformity of shape or posture. If there are allegations of mistreatment and an interviewee still has marks and they agree for monitors to inspect them, monitors should try to record as much detail as possible. This should, if possible, be done by a medical member of the monitoring team. Monitors may want to take a photograph, noting the site, size, shape, colour and type of the injury. Some people are of the view that a written note is as good as a photograph. Monitors can ask if there was any medical assessment or treatment given, and can then try to find documentation of this and/or speak to the doctor who was involved.

It may be that in talking about their situation, a patient/resident tells a monitor that he or she feels bad and wants to hurt themselves. This puts the monitor in a difficult ethical position, having told the patient/resident that everything will be kept confidential. The monitor will have to balance this with the first principle of human rights monitoring of 'do no harm'. The monitor may want to explain to the patient/resident that their safety is very important, and that the monitor has to tell the staff what she or he has told them. If the monitor tells the staff anything, it should be limited to the harm and not to previous information unrelated to the harm. A way of doing this is by asking the patient/resident whether they would agree to the monitor inviting a member of staff to come into the room so that the patient/resident, the staff member and the monitor can discuss the situation.

In some circumstances, monitors may decide that the information they have collected on ill-treatment urgently needs to be known by others, so that the injuries can be treated. Monitors may therefore want to share and discuss findings with the director of an institution or someone else in authority. It is important to first discuss this with the individual(s) who have divulged or shown evidence of ill-treatment. It may also be useful to seek legal advice about the particular abuses monitors have encountered.

### ● Dealing with people with delusions

A delusion is a fixed and demonstrably false belief. Delusions are sometimes symptoms of some mental health problems, including psychoses. An example of a delusion is: 'I am Jesus Christ'. Monitors should not attempt to convince the patient/resident that their belief is false, because it is true to them. Instead, monitors should say something like 'I can't prove that and I am not going to try, but perhaps you could tell me how that makes you feel?' Monitors should be aware that patients/residents with delusions can also be victims of human rights abuses, and a person who thinks he is Jesus Christ may not be delusional about all topics. People with delusions should not be simply dismissed out of hand by monitors. If someone says: 'The staff are poisoning my food', this is probably not true. But it is worth asking staff if they are putting anything in the food. Even if it is not true, the delusion may be related to medication being given against the person's will.

### ● Dealing with intrusive staff

At the beginning of the visit, the head of the monitoring group should explain that the monitoring involves holding interviews with people, including patients/residents, and that it is vital that these discussions happen in private, which means out of the earshot of any staff member. If the director has any problems with this, the head of the monitoring group should note the concerns, and address them directly at that time. The head of the delegation should not give up at this point. He or she should do everything to ensure that interviews happen in private, because monitors will find it difficult to proceed without this guarantee. If the director refuses to give permission, the head of the delegation may want to telephone the person who gave permission to carry out the visits and ask them to explain to the director that the interviews must happen in private. At times, it may be important to tell the director that the report will need to include the fact that he or she refused to co-operate. Sometimes, merely informing the director of the intended next steps may facilitate co-operation.

Sometimes, staff on wards/departments will not want monitors to speak to patients/residents alone. This must be resisted in all circumstances and with vigour. Monitors can say something like: 'The rules which I have to work under are such that we have to speak with patients/residents in private. I'm sure that you understand that I need to follow these rules.'

The staff may claim that the patient/resident is 'too violent' or 'too mentally ill' for them to allow the monitor to speak to them. Monitors should listen to what staff are saying, because it could be true that a person has recently been violent: the circumstances are always unique and the monitor should make a judgment. If the monitor would like to proceed, he or she could say something like: 'I understand that you are concerned about my safety, but I am not a member of staff here, so you do not need to take responsibility

for my safety because I take full responsibility for my own safety and am willing to sign a paper to document this.'

Sometimes, staff will say that monitors need the permission of the legal guardians of the patients/residents before the monitors can talk to them. For people whose legal capacity has been deprived or restricted this may well be true, according to national laws. Monitors need to have discussed this in advance and be clear about what their strategy is. In some institutions where all of the residents are under guardianship, this is simply a way for staff to stop the monitors from talking to any of the residents, as contacting each of their guardians will be a time-consuming task and may jeopardise the purpose of the monitoring. In other instances, monitors may have statutory powers to talk to any person in a place of detention, and can use their legal powers to override the attempt by staff to block the monitors' attempts to speak to residents.

Sometimes staff members are genuinely scared of allowing monitors to speak with residents because staff members have never experienced human rights monitoring. In these cases, monitors should calmly and politely explain the purposes and methodology of human rights monitoring and emphasise that speaking to patients/residents in private is a crucial aspect of the venture. Having a psychiatrist on the monitoring team will help to allay fears that the human rights monitors are outsiders without any mental health expertise, whose only intention is to expose bad things in the institution.

### ● Recording information

Monitors should record the place, date and time of the meeting, and the people present. However, they should not spend the entire time looking down and taking notes. The conversation should flow easily, and monitors should have good eye contact with interviewees. Monitors should therefore have questions in mind relating to an entire topic, and ask them in an appropriate order, rather than artificially ensuring that each piece of information obtained is recorded before moving on to the next topic. This method will help monitors to record and verify information from a number of different sources. Monitors may want to work in pairs, with one person leading the conversation and maintaining eye contact, and the other person taking notes. Some monitors make audio recordings of a testimony or interview. There are disadvantages to doing this. A higher level of consent must be obtained to record someone's voice than interview them without recording their voice. Audio recordings can put people off speaking, and it is extremely time-consuming to go through a recording at a later date (see Section 6.4, How to record information).

### ● Ending the interview

Ending the interview is important, especially as the issues talked about may be emotional and personal. Ending the meeting well includes allowing time at the end for the interviewee to take the situation in and to compose himself or herself. It is important to give the interviewee a chance to ask questions. This is also a useful time for finding out from the interviewee about other people with whom monitors should speak, things which monitors should see, or issues which monitors should find out about. Monitors should thank the interviewee for their time and help.

People may ask monitors to return and visit them, to bring them things, to give them money, help them leave an institution, or to smuggle a letter or another item outside the institution. As much as monitors will want to help and have good intentions in doing so, it is important to be realistic and clear about the rules they work under and what it is they are not allowed to do: this will differ from one monitoring team to another.

### ● Keeping safe

It is important to realise that violence by people with mental health problems is rare. Aggression and violence in psychiatric settings does, however, happen. Monitors should take care to minimise the risks to themselves. In rooms where interviews are taking place, it is a good idea for the monitor to invite the patient/resident to sit further away from the door, and for there to be a table between the monitor and the patient/resident. This would enable the monitor to leave the room if she or he feels unsafe.

In the event that the monitor would like to end the meeting because of safety concerns, it is possible to say to the patient/resident that the monitor would like to take a break in order to speak to some other people, and that they might come back later. The monitor should simply leave and discuss the situation with others.

A final safety issue is ensuring that monitors have appropriate immunisations against infectious diseases such as tuberculosis, where applicable and appropriate. In an institution, monitors should cover any wounds on their hands, and it is advisable to use anti-bacterial wipes or gel. In some countries, there are special psychiatric departments for patients with TB. Monitors will need to decide how (not if) to speak with staff and residents in these departments. This could be done in a well-ventilated room, or through a window. Monitors are advised to seek professional input from a specialist doctor before deciding how to proceed.

## 6.2 Method 2 Observation

Institutions are sometimes overwhelmingly large, and with many things going on at the same time it is easy to forget to observe what is happening. When observing, the monitor's first hand experience generates the evidence. Detailed and objective recording must be made so that the observer's experiences can be taken as credible, rather than disregarded as unreliable.

Observation is about using one's senses: all that a monitor can see, hear, smell, touch and taste during the visit. It includes, in particular, visiting all the premises and facilities, and being able to carefully inspect and record detail in a wide variety of rooms. The prompt questions in Section 9 of the Toolkit contain a number of issues for which observation will be the only method of obtaining the information. Finding out the size of a bedroom means that the monitors should take a tape measure. Assessing the cleanliness of a toilet means more than saying: 'The toilets were not clean', which is a subjective conclusion, not an objective description. Monitors need to describe the toilet to paint a picture in a descriptive way of what 'not clean' actually means.

Staff may want to give the monitors an official tour of an institution. This may involve – literally – carpets being laid out in advance. While this is useful, the tour is likely to be superficial, and likely not to show monitors the 'worst' areas of the institution. Therefore, monitors should consider what they are observing, and what it is they are not being shown. Asking patients where they keep the patients/residents who do not behave may alert monitors to areas of the institutions which they have not been shown.

Another point to observe during an official tour is how patients/residents relate to the staff member showing the monitors around. There may appear to be a comfortable relationship, or there may be no contact, or avoidance. Similarly, the attitude and behaviour of other staff may be revealing: for example, do the staff members knock on bedroom doors before entering? Do they address the patients/residents courteously?

It is common that during a visit from outsiders, there is an 'observer effect' and staff members are on their best behaviour in order to impress. Monitors should not take such behaviour as typical. Monitors can expect that problems encountered when they are visiting will be worse when they leave, and worse during the nights (for this reason alone it is a good idea to go back during the night if this fits into a monitoring team's schedule). For example, if a staff member is seen overlooking violence between residents, it is logical to think that at other times more serious violence would be overlooked. Typical staff behaviour is often revealed towards the end of a visit, when staff may be tired. Seemingly small behaviours may change, such as staff no longer knocking on a resident's bedroom door before entering. Staff may address patients/residents courteously for the first

couple of hours of a monitoring visit, but then, as they become more comfortable with the monitors, staff may slip into their usual routines. Observing this requires monitors to be alert for the entire duration of the visit.

Ideally monitors should spend a couple of days in an institution in order to observe more of the reality of daily life. More time allows residents to get accustomed to the monitoring team member(s), and thus more likely to open up and talk. Failing this, it is still useful to have some unstructured time just 'hanging out' in the institution. As noted above, it is advisable to visit an institution outside of official working hours, when the director and day staff have left. It is often during the night (which may start at around 4pm in some institutions) when there are fewer staff on duty that human rights may be restricted.

### 6.3 Method 3 Reviewing documentation

There are many types of written material that can provide evidence in a report. There are some topics covered during the monitoring visit, where it is advised that monitors obtain copies of written materials (documentation). These may include:

- Policies, plans, contracts, consent sheets, information booklets etc, given to patients/residents upon arrival.
- Policies and statements produced by an institution (eg restraints policy, suicide prevention policy, health and safety policy, staff development policy).
- Records of the number of people in the institution, and the numbers who have left, and where they have gone on to (eg the community or another institution).
- Medical and nursing records. These documents are confidential, so the institution may correctly be reluctant to show them to monitors. In this case, monitors could ask the staff to allow patients/residents to access their own medical records, or monitors could ask the medical member of the monitoring team to talk with the treating doctor.
- Death certificates or other mortality information.
- National information on the number of people detained under mental health legislation; residing in mental health settings; numbers in social care institutions; or the number of people under guardianship, for example.

Typically, the obligation of recording information is regulated by law and, depending on the country, certain documents may be required in order for the institution to hold a license to operate as a mental health or social care facility. In other countries, such information simply does not exist because it is not counted, or information is not collated by a central governmental body. Monitors may want to consider using freedom of information legislation (if it exists) and submitting formal requests under the relevant provisions of such a law in order to obtain the desired data and statistics.

Before the visit takes place, monitors can ask for data from the institution and/or governmental authorities (see Section 7, Step 4, Gather background information). Gathering this data will help the monitors know what sort of institution they are visiting, and what, roughly, they can expect.

Following the visit, monitors need to analyse these documents, both against the observed reality supported by information provided by residents, as well as against the general practice described by staff. At this stage, it might be needed to arrange a second meeting with the director, so that further questions can be asked once more information has been gathered. Monitors should be aware of the obligation under Article 31 of the CRPD of the need for States to collate statistics and data in order for progress of implementing the Convention to be monitored, and to identify and address the barriers faced by persons with disabilities in exercising their rights. Such information needs to be disaggregated as appropriate. These are important details to insert into a resultant monitoring report.

## 6.4 How to record information

### ● Note-taking

Taking notes during the monitoring visit is the most typical method for recording information. The resultant notes will help the monitor to reconstruct the visit and create accurate reports. Different monitors have different note-taking styles, and it is important to choose an approach most suitable for the individual.

Note-taking should not distract the monitor from listening to interviewees, nor should it make the interviewee feel uncomfortable. Different note-taking methods may be used to ensure a smooth flow to conversations. One method is to listen and observe a specific situation without taking notes at the time, and then quickly summarise the information in note format before moving on to the next topic. If notes are taken during a discussion, the use of keywords can be helpful, structuring the collected information in ways most useful for writing the report later. As noted above, monitors may prefer to carry out important discussions in a team of two people, with one monitor leading the discussion and the other taking notes.

Monitors should discuss in advance whether they want to have copies of the prompt questions contained in Sections 9 of the Toolkit, and whether they want to have extra pages available to take further notes.

Whichever note-taking method monitors decide to choose, it can be beneficial to take short breaks during the visit to review what information has already been collected, fill in possible gaps, select issues which need further discussion and share important findings with other members of the monitoring team.

### ● Visual and audio recordings

Visual (still photographs and video) and audio (tape or digital) records can be useful in supporting the accuracy of statements, and in helping an audience to appreciate a situation. They can also be useful materials for the media to use. At times, filming in particular can assist co-operation. Sometimes people welcome the potential publicity and excitement, and they may feel there is a greater degree of accuracy, as ‘the camera never lies.’ However, it is also true that the camera never shows the full context, and a description can often be more powerful than a photograph.

In considering visual and audio recordings, the privacy and confidentiality of patients/residents should be protected. Monitors need to decide whether they are comfortable showing people’s faces and identifying features. This might depend on national laws and customs, and monitors should take into account the views of national and local organisations of people with mental health problems and people with intellectual disabilities.

Showing a person’s face is often more powerful as it captures a human being’s facial expressions. The photograph may portray an undignified scene, and having a person’s face may be the least de-humanising way to retain in a photograph

a patient/resident’s dignity, rather than putting a black strip across people’s eyes, or blurring their face so as to make them unidentifiable. A way to get round this is to depict in a photograph the back of people’s heads, or show their hands, to demonstrate that there are real human beings living in this place. Another method is to use a crowd scene where no-one is identifiable – it is quite difficult, however, to really ensure that people are not identifiable.

Sometimes, photographs which include faces have been taken but are not used for any public purpose. On other occasions, people’s faces have been shown, and it is argued, that although their right to privacy is being infringed, this is less abusive than the other abuses they are suffering in the institution. Different organisations have different policies about how to ask for consent, how to use photographs, and whether to use photographs at all. It is for the monitoring team to be clear about whether they would like photographs in the resultant reports, and to have a clear idea about the reasons why, as well as the methods of gaining consent. Do not take photographs if the individual service users do not want their photo taken. On the other hand, people may ask to be filmed or photographed. Patients/residents may ask for copies of photographs to be sent to them: monitors should only promise to do this if they have every intention and means to actually do so.

Even if monitors have permission from individual patients/residents to take photographs or film, monitors should also ask permission from the staff. This avoids situations of confrontation and antagonism. One of the purposes is to provide helpful and constructive feedback to the staff so they can improve the services.

## Section 7 **Ten steps of human rights monitoring**

Having looked at the principles of monitoring and the primary methods of interviewing, observation and reviewing documentation, the Toolkit outlined some of the methods of capturing the information received. This Section provides a step-by-step guide through the entire process of monitoring human rights in mental health and social care institutions. It contains questions which monitors need to ask themselves, and there is space for monitors to write their answers down. It is intended that this will help monitors to think through each of the steps and carry out planning in advance of each step. The aim of this Section is to provide monitors with practical assistance in the monitoring cycle.

**The steps of human rights monitoring contained in this Section are:**

- 1. Set objectives for the monitoring**
- 2. Build the monitoring team**
- 3. Train the monitors**
- 4. Gather background information**
- 5. Plan the visits**
- 6. Carry out the visits**
- 7. Write the report**
- 8. Disseminate the report**
- 9. Evaluate the process**
- 10. Plan future visits**

### Step 1 **Set objectives for the monitoring**

Formulating a monitoring concept is useful so that monitors ensure that limited financial and time resources are used effectively, and that stakeholders understand the project. Conceptualising is also crucial in order to pitch project ideas to potential funders and to government where they are direct partners in the monitoring.

In Section 4, the purpose of human rights monitoring has been explained, followed by a list of possible follow-through activities for the results. Building on this knowledge, the first step in carrying out human rights monitoring is to set the specific objectives of the monitoring.

We recommend that the objectives are SMART, that is Specific, Measurable, Agreed, Realistic and Time-bound.

**At this point monitors also need to consider various practical issues, such as:**

- **What are the social,** technological, economic, environmental, and political contexts in which the project will take place?
- **Can the monitoring team benefit** from engaging other external people such as experts, writers, layout experts, proof-readers, translators, psychological support persons, publication experts etc?
- **Who will be the target audience(s)** of any resultant reports?
- **What is the time frame** for the monitoring? What can be realistically done during that time period, considering the time required for planning the visits (approximately one week), going on a visit to one institution (usually one or two days), writing reports after the visit (approximately one week per institution) and then consolidating the findings and summarising the reports for the target audience(s) (about two to three weeks).
- **How much is the budget,** and what resources are still required? From where will further funding be sought?
- **What follow-through activities** do monitors need to plan in order for the recommendations of the report to be met?

## Step 1 Set objectives for the monitoring

To answer these questions, monitoring groups will need to carry out preliminary investigations. This may involve speaking to people who have been, or are, involved in this field, and obtaining all materials which have already been produced.

When deciding on the aim and objectives of the monitoring, you should consider what the most serious problems are, how much monitoring is manageable, and what is likely to make a difference. It is useful

to remember that monitoring has the potential to be effective because it enables arguments to be supported by evidence. In order to ensure that enough supporting evidence is gathered, it may be worth narrowing the scope of the monitoring to, for example, one human rights area, or one geographical region. The golden rule is that monitoring and the follow-up always take longer than planned!

Monitors can write the objectives of the monitoring in the table below:

| Specific objective | Measured how? | Agreed by whom? | Realistic how? | By when? |
|--------------------|---------------|-----------------|----------------|----------|
| 1.                 |               |                 |                |          |
| 2.                 |               |                 |                |          |
| 3.                 |               |                 |                |          |
| 4.                 |               |                 |                |          |
| 5.                 |               |                 |                |          |

## Step 2 Build the monitoring team

Monitoring should always be carried out in a team, which is a group of people working towards a common goal. Working in a team means that there will be more people to pick up information; more people to see and hear things; more monitors to divide and explore different areas of the institution; and a multi-disciplinary perspective. Having a team enables mutual support which given that monitoring is always stressful and sometimes extremely distressing, is particularly important (see ‘Self care’ under Step 6, Carry out the visits).

At Section 5.4 of the Toolkit, it was suggested that it is a principle of human rights monitoring to ‘build a credible team’, and that the monitoring team should

be multi-disciplinary and should consist, at the minimum, of a person with service user background, a person with a medical background and a person with a human rights background. Monitors should make sure that all members of the monitoring team are thoroughly trained in the monitoring methodology (see Step 3 Train the monitors).

Monitors may find it helpful to list potential members of the monitoring team before contacting them, bearing in mind Section 5.4 of the Toolkit. After the table is completed, monitors may wish to review whether the monitoring lacks particular skills or expertise. Monitors may want to bring in experts to fill any skills gaps.

| Name | Background | Particular skill/expertise |
|------|------------|----------------------------|
|      |            |                            |

## Step 3 Train the monitors

Carrying out human rights monitoring visits requires an equal level of understanding and preparedness by all monitors on the monitoring team. Holding a team-training is a good start to ensure this.

Considering the density of the information covered by this Toolkit, and in order to allow for sufficient time for monitors to digest and reflect on the information contained within, at least three days should be set aside for the training. In an additional two-day session, the monitoring team can further develop the specific objectives for their monitoring visits, and follow the next steps of human rights monitoring set out in the Toolkit.

| Session number | Content  | Notes about who can lead the session, how much time is needed and what equipment is necessary |
|----------------|--|---|
| 1              | Introduction to human rights monitoring <ul style="list-style-type: none"> <li>■ What are human rights</li> <li>■ Why monitor them?</li> <li>■ Difficulties of monitoring human rights in institutions?</li> </ul>   |   |
| 2              | Monitors' expectations, experiences and expertise <ul style="list-style-type: none"> <li>■ Discussion of fears and challenges</li> <li>■ Discussion on working together: users and ex-users of psychiatric services</li> </ul>   |   |
| 3              | Human rights and disability <ul style="list-style-type: none"> <li>■ Discussion of current issues and specific local issues</li> <li>■ UN Convention on the Rights of Persons with Disabilities</li> <li>■ Gain familiarity with the prompt question groupings</li> </ul>  |   |
| 4              | Human rights monitoring <ul style="list-style-type: none"> <li>■ Purposes</li> <li>■ Principles</li> <li>■ Techniques</li> </ul>   |   |
| 5              | Practise interviewing skills <ul style="list-style-type: none"> <li>■ In groups of three (person 1 assumes the roles of interviewer, person 2 the interviewee (staff or resident), and person 3 is an observer), practise interviewing skills. The observer's role is to provide feedback to the interviewer picking up on both positive and negative practices. Everyone should play each role at least once.</li> <li>■ To prepare for collecting information through observations, monitors should go through the topics and prompt questions presented in the Toolkit and discuss the specific information that will be collected by observations. Once done with the simple observations, monitors should also discuss how they can make observations on such difficult issues as power, communication, attitudes (a documentary on institutions may also be used for practising)</li> <li>■ Discussion ethical and sensitive issues</li> </ul> |   |
| 6              | Practise observation skills <ul style="list-style-type: none"> <li>■ Ask participants to list all of the items/issues they could possibly observe in an institution</li> <li>■ Ask participants to describe the room they are in now</li> </ul>  |   |
| 7              | Topics to discuss in more depth about disability and human rights. These might include <ul style="list-style-type: none"> <li>■ User perspectives on human rights</li> <li>■ Community-based services</li> <li>■ Restraints and seclusion</li> <li>■ Right to health</li> <li>■ Regional human rights law</li> </ul>   |   |
| 8              | Dealing with difficult situations <ul style="list-style-type: none"> <li>■ Staff intrusions</li> <li>■ Delusions</li> <li>■ Risk of harm</li> <li>■ Disclosures of self-harm or harm to others</li> </ul>  |   |

## Step 4 Gather background information

Monitors need to obtain and ensure they have an understanding of legal information, such as legislation, ministerial decrees and other sources of law, as well as mental health and social care policies. Knowledge of the relevant laws and policies is critical in order for the monitoring team to be credible in their analysis. A review of the relevant laws should highlight the positive aspects as well as their limitations and problems. Monitors can use this analysis to calibrate the monitoring questions, and to educate the monitoring team. A thorough understanding of the relevant laws and policies will increase the accuracy, and therefore the credibility and likely impact, of any resultant report.

The relevant laws and policies will vary according to the country of study, and also according to the focus of the investigation. Laws that may be relevant include: the constitution, health law, mental health law, civil code, civil procedure code, criminal code, criminal procedure code, family code, guardianship/decision-making laws, social care law, anti-discrimination law, or laws related to human rights such as on voting, marriage, rights to housing, employment and education.

Additionally, there may be legally-binding ministerial decrees or other regulations that have the force of law issued by a minister, rather than agreed by parliament. Laws may be found on the internet, in libraries, and through government offices. If the monitors are conducting monitoring in a country other than their own, it is worth obtaining official or unofficial translations of laws into a language which they can understand. English translations are always useful for presenting findings to international bodies in cases where the monitoring team thinks international attention would be useful.

Monitors should have a familiarity also with international (such as the UN Convention on the Rights of Persons with Disabilities, see Section 2.3) and regional human rights treaties ratified by the State in which the monitoring will take place. Monitors should analyse the domestic provisions against these international legal instruments to find out the extent to which national laws comply with the country's Constitution as well as international human rights law, especially where such law is binding in the country of investigation.

Legal analysis may be a daunting task for non-lawyers. There are various ways it can be made easier. Firstly, some legislation may not be as difficult to read or understand as one would imagine. Secondly, there may be local organisations and/or lawyers who already have, or are willing to, conduct legal analyses. They may be able to summarise the law and indicate problems and loopholes of the law. They may also be able to provide information on cases that have come to court, or are in progress, or that could be brought in the future. Thirdly, it is very useful to have a human rights-savvy lawyer as part of the monitoring team.

In addition to acquiring a thorough understanding of the relevant legislative framework, monitors need to gather and digest information about the mental health and social care system in the relevant country. There are various sources for such information, for example:

- Reports by intergovernmental organisations, such as the UN and the Council of Europe (especially important to look at are reports by the European Committee for the Prevention of Torture, and concluding observations by monitoring mechanisms such as the European Committee on Social Rights, and the UN Convention on the Rights of Persons with Disabilities).
- Reports from domestic and international non-governmental organisations, national human rights institutions or ombudsman offices. Especially interesting would be shadow reports submitted to relevant treaty monitoring bodies.
- Press and media reports and features.
- Academic books, journal articles, including unpublished materials such as masters and doctoral theses.
- Governmental information. For example, statistics on the number of people under guardianship, detained on mental health disability grounds, or residing in social care institutions. Also any governmental policies contained in green papers, white papers or ministerial speeches/statements.

Monitors will undoubtedly need to meet and hold discussions with people with experience and knowledge of the issues that will be monitored. In particular there is no substitute for talking to people who have been directly affected by the system, namely people with mental health problems and intellectual disabilities and their representative organisations. The checklist opposite is intended as a guide for monitors to collect information well before planning or embarking on any visits.

## Step 4 Gather background information

### 1. Institutions and care settings

a. How many of the following are present within your country?

- i. Psychiatric hospitals
- ii. Psychiatric departments in general hospitals
- iii. Care homes for adults with mental health problems

b. What are the total numbers of institutions?

c. What is the total number of beds in these institutions?

d. What are the main bodies managing these institutions?

What official accountability structure is there? (for example is there a management committee, or a system of checking by the ministry, or are there no external checks on the management?)

e. How is funding provided to these institutions?

- i. What is the source and amount?
- ii. Are budgets public documents?

### 2. Independent monitoring

a. Does any independent authority/body monitor the human rights of each of these institutions?

b. What are the names and contact details of these bodies?

c. How often do they visit the institutions?

d. Who does the monitoring? (psychiatrists, lawyers, service users, etc.)

Does the body / bodies issue public reports about the visits?

If yes, obtain copies of all of the visits in the last five years.

e. Has your country ratified the Optional Protocol to the UN Convention against Torture?

If yes, has the country established or designated a 'national preventive mechanism'?

### 3. Alternatives to institutions

a. What alternatives exist for people with mental health problems outside of institutional care?

b. What alternatives exist for people with intellectual disabilities outside of institutional care?

c. What is the history of these alternatives, in other words when were these services developed?

d. How many people use these different types of services?

e. Who or what pays for these services?

### 4. Legal capacity

a. What legal provisions does your country have which regulate how financial, health and welfare decisions are taken by/for people with disabilities who do not have functional capacity? This might be, for example, guardianship laws, mental incapacity laws, or advance directives.

b. When was this system introduced in your country?

c. Has the system been reformed? If yes, what was the nature of the reform? List the rights which are removed from the adult when s/he is placed under guardianship or other forms of legal protection.

### 5. Involuntary admission and treatment procedures

a. Under what circumstances can your country's psychiatrists detain a person for mental health reasons? You will have to look in the mental health law, or general health law, or perhaps the civil code. Summarise in writing the criteria set out in the law.

b. What is your opinion about these criteria? For example, are they too broad, too narrow, too specific, not specific enough? How would you re-word the criteria if you were in government?

c. Are advanced directives for mental health care and joint crisis plans used? How does this work?

### 6. UN Convention on the Rights of Persons with Disabilities

a. Has your country signed/ratified the CRPD and the Optional Protocol? (find out by looking here: [www.un.org/disabilities/](http://www.un.org/disabilities/))

b. If not what are the plans to do so? You may have to call up the Ministry of Foreign Affairs.

c. What, in your opinion, are the three articles of the Convention which will be most problematic for your country to comply with? Why?

## Step 4 Gather background information

### 7. Media

- a. Using internet searches, gather 10 news stories about any aspect of human rights of people with mental health disabilities and intellectual disabilities in your national or local media.
- b. Do any of these stories relate to any institutions?

### 8. Institution information

The following are pieces of information which can be requested from each of the institutions which the monitors plan to visit.

- a. Number of beds (disaggregated into units: admissions, chronic, forensic, etc).
- b. Number of people detained under mental health legislation.
- c. Number of people deprived of legal capacity/placed under guardianship.
- d. Ages of patients/residents (useful age bands are: under 18s, 18 to 30, 30 to 60, 60+).
- e. Number of female patients/residents, number of male patients/residents.
- f. Average length of stay.
- g. Longest length of stay.
- h. Diagnostic breakdown (eg number of people diagnosed with depression, intellectual disabilities, dementias etc).
- i. When was the institution built/opened?
- j. Geographic location:
  - i. Nearest town (in km, using roads)
  - ii. Nearest shop (in km, using roads)
- k. Funding (what is the total budget of the institution and how does it get its money? On what is the money spent?)
- l. Relationship to academia:
  - i. What sort of links does the institution have to any universities? Name the university/ universities and describe the relationships.
  - ii. What sort of research or medical trials does the institution conduct?

### 9. Restraints and seclusion

- a. What forms of physical and chemical restraints or seclusion are used in your country?
- b. How is their use regulated in law?

### 10. Anti-discrimination laws

- a. Does your country have an anti-discrimination law?
- b. What areas does the law cover (eg education, employment, healthcare, housing etc).
- c. On what grounds is discrimination proscribed (eg race, ethnicity, gender, sexual orientation, age, social status, disability, other status).
- d. Does the law include protection against discrimination on grounds of mental health disabilities?
- e. Does the law include protection against discrimination on grounds of intellectual disabilities?

### 11. Organisations of people with mental health problems

- a. What organisations of people with mental health problems exist in your country?
- b. What are the contact details of these organisations?
- c. What do these organisations do? (for example do they provide services, work on human rights, conduct advocacy in institutions, monitor human rights in institutions, lobby at the parliamentary/governmental level, comment on mental health policies, or try to reform services?)
- d. What sorts of information can these groups provide?

### 12. Organisations of people with intellectual disabilities

- a. What organisations of people with intellectual disabilities exist in your country?
- b. What are the contact details of these organisations?
- c. What do these organisations do? (for example do they provide services, work on human rights, conduct advocacy in institutions, monitor human rights in institutions, lobby at the parliamentary/governmental level, comment on mental health policies, or try to reform services?)
- d. What sorts of information can these groups provide?

## Step 5 Plan the visits

Monitors will need to plan the specifics of where and how to conduct the monitoring. This involves considering and deciding upon the following issues.

- Select a person to be in charge  
Assign one person to be the head of delegation. Some tough decisions need to be made sometimes, and having pre-agreed leadership in these cases is very useful.

- Choose the institutions to visit  
Section 1 of the Toolkit lays some of the types of places which could be classed as a ‘mental health institution’ or ‘social care institution’. The monitoring team will have to find out about different institutions in the particular locality, and assess whether to visit a range of different institutions, or several of similar types of institution.

The monitoring team may be tempted to visit the institutions which are notoriously ‘bad’. It is a better strategy to monitor a representative sample, because then the ‘bad’ institutions will be logically unable to claim that they cannot make improvements if the monitoring report contains remarks on visits to ‘better’ institutions.

The table below can be used to list the types of institutions which may be selected to be visited. The table can be expanded as necessary.

- Announced and unannounced visits  
The monitoring team will need to have permission at some level to carry out the visits. The monitoring body may have statutory powers to enter such institutions, or it may be a negotiated access (see next section). Announced visits mean that the institution knows that the monitoring team is coming on a particular day and time. Unannounced visits mean that there is no warning of the visit. There is also a subtler form of unannounced visits whereby the monitoring team informs the institution that during a certain period (it could be a calendar year, for example) it will visit, without giving the exact date. It is generally accepted that monitors get a truer account of reality during unannounced visits.

Announced visits on the other hand, have the advantage of allowing an institution to make real progress since a former visit, so announced visits can act as a quality control if the management takes the process seriously. Monitors could use the table to mark which institutions will be visited on an announced basis, and which on an unannounced basis.

|   | Name of Institution | Nearest town | Number of beds |
|---|---------------------|--------------|----------------|
| Psychiatric hospitals   | 1                   |              |                |
|   | 2                   |              |                |
|   | 3                   |              |                |
|   | [etc]               |              |                |
| Psychiatric departments of general hospitals                        | 1                   |              |                |
|   | 2                   |              |                |
|   | 3                   |              |                |
|   | [etc]               |              |                |
| Social care institutions for people with mental health problems     | 1                   |              |                |
|   | 2                   |              |                |
|   | 3                   |              |                |
|   | [etc]               |              |                |
| Social care institutions for persons with intellectual disabilities | 1                   |              |                |
|   | 2                   |              |                |
|   | 3                   |              |                |
|   | [etc]               |              |                |
| Other types of institution (country specific – please list)         | 1                   |              |                |
|   | 2                   |              |                |
|   | 3                   |              |                |
|   | [etc]               |              |                |

### ● Logistics

Planning the logistics will depend on whether the monitoring visits are unannounced or announced. When planning the timing of visits, it is useful to leave some spare time and have some flexibility, as frequently, findings from one visit will result in new ideas needing to be pursued.

Depending on the size of the institution, a visit can take one day to two-three days. The European Committee for the Prevention of Torture usually takes about one-and-a-half days per institution. One full day (eight to twelve hours) is the absolute minimum. There is no point in carrying out a short visit: reports will reflect superficiality. Visits usually take longer than expected, so allow plenty of time and flexibility to be able to carry out the visit according to what monitors find. Monitors should ensure that someone is responsible for the logistics. This includes making arrangements for travel, accommodation, daily living costs, interpreters, and visas, if necessary for foreign visitors.

### ● Gaining access

Permission at some level needs to be obtained even for unannounced visits. This can be done in a variety of ways. National preventive mechanisms established by a State under their OPCAT obligations will have access to all places of detention by virtue of their mandate, which is likely to be enshrined in domestic legislation. Similarly, the European Committee for the Prevention of Torture has an international statutory right to enter places of detention and speak with detainees in private, as does the UN Sub-Committee for the Prevention of Torture. For all other bodies there is likely to be some negotiation about permission to carry out visits, especially unannounced visits. Monitors wishing to obtain such permission are encouraged to remind the authorities of the purpose of monitoring: to highlight problems and offer solutions so that human rights of people inside institutions are improved. Governments may refuse on the basis that unannounced visits are a hassle for the institution. In this case, monitors can remind the government that a little institutional hassle is far outweighed by human rights improvements. If permission for unannounced visits is refused, monitors should publish the facts

around such a refusal in their monitoring report. If visits are carried out on an announced basis, monitors should have in their minds that they are likely to be observing a planned reality.

Gaining access can be difficult for non-established bodies that have no official mandate to conduct visits, and there may be official and personal resistance to attempts to visit, such as permission from the director only to visit specified parts of an institution. Such resistance may manifest itself overtly (such as a clear refusal in writing) or covertly (such as officials being unavailable, needing to seek permission from seniors, not responding to letters, arranging to meet but not showing the whole institution, or supplying drinks to the monitoring team to encourage them to spend as much time in the director's office rather than talking with other staff and patients/residents).

Generally speaking, the further up the hierarchy that permission has been obtained, the more others in the system are likely to be co-operative. Monitors are advised to seek permissions from governmental ministers or their regional equivalents. Failing that, the institution's director can be approached.

Often introductions and personal connections can speed up the process. In official requests for permission to enter an institution, it can be useful for monitors to explain the potential benefits of the monitoring (for example, in providing information and in making constructive suggestions for changes and improvements in the service – after all, many staff members of mental health and social care institutions do actually want to provide good services). It can be helpful to explain the credentials of the monitoring organisation and any previous work it, or its members, have been involved in.

In negotiating access, monitors could consider promising the institution that they will receive an advance copy of the report in order to correct any factual mistakes. Generally the more constructive monitors are, the more likely it is that authorities will offer positive responses. Monitors should keep copies of all official letters sent, and letters received, in case these are needed later. Monitors should take with them copies of permission letters on all monitoring visits.

This table can be used to write down how access to the institutions will be sought.

|  |  |
|--|--|
| What kind of permissions are required to visit the range of institutions chosen? |  |
| Who can provide the permissions?   |  |
| Who from the monitoring team is responsible for seeking the permissions?         |  |

## Step 6 Carry out the visits

A typical monitoring visit will most likely involve the following, but not necessarily in this order:

- Interview with the director or other senior management.
- Tour of the entire institution.
- Targeted and in-depth observation in a small number of departments/wards.
- Interview with management at the service level (eg clinical director or head of a department) and staff at point of service delivery.
- Interviews in private with several patients/residents.
- Review of documents and policies.

This step should be read in conjunction with Section 6 about methods of human rights monitoring.

### ● Briefing

Before each visit, the head of delegation should conduct a thorough briefing session for all monitoring team members. This should cover the basic facts of the institution, the duration of the monitoring visit, the role of each of the monitoring team members, and what to do if there is a problem.

### ● On arrival in the institution

On a monitoring visit, monitors are likely first to meet the director of the institution and be shown into his/her office. Explain who you are (avoiding any accusatory language. It is better to say 'we are here to look at some aspects of human rights' than 'we are here to do a torture inspection!' or other inflammatory language!)

### ● Get into the worst part of the institution immediately

Especially on unannounced visits, it is important to split up within five minutes of entering the institution. One person can stay with the director of the institution as a matter of courtesy, and the other members of the monitoring team should immediately seek out the 'worst' part of the institution. The reason for this is that as soon as a monitoring team arrives, the staff will be alerted and will take steps to make things look better: this could include washing blood off the floor, removing restraints, locking away 'troublesome' patients, hiding the stick which staff use to threaten patients, and so on.

Monitors can ask patients: 'Where are aggressive patients?' In some institutions, there is one particular place which is feared by patients/residents and it will become clear from the answers where this is. If there is no information from patients/residents, monitors should head for the seclusion/isolation room, the locked wards, the admission units, the chronic wards for people who have been in the institution several years, or the forensic psychiatry unit. These are places where human rights violations are most likely to happen.

### ● Take a tour

Monitors should then go on a quick tour of the institution covering all the departments/wards. Even if it is a big institution, the monitors should walk through the corridors getting a sense of the place. It will be much easier for the rest of the visit to gauge whether one particular unit/department is 'better' than others. Monitors can then choose which units/departments in which they would like to spend more time.

### ● Engage with the director and staff

The monitor who has remained talking with the director should explain the purpose of the visit in a non-confrontational manner that will encourage the co-operation of the director of the institution and will not jeopardise access to all parts of the institution. Monitors can emphasise that the purpose is to find out how the institution works, to listen to problems from the perspectives of the staff and the patients/residents, and to have a constructive dialogue with the institution.

The head of delegation could explain who the members of the monitoring team are and what the monitoring visit aims to achieve, how long the monitoring will last, and what sort of co-operation the team expects from the staff. The independence of the monitoring from the institution should be emphasised. Monitors should be careful not to leave the staff with elevated hopes of what the monitoring can achieve. The head of the monitoring delegation should leave contact details of the monitoring secretariat or office, and explain what further contact there may be. The delegation should ask for permission to make notes or to record the interviews. For tips on how to deal with staff blocking private conversations with patients/residents, see Section 6.1, Dealing with intrusive staff.

### ● Give immediate feedback

The director may ask for feedback after the monitoring visit about what the monitors found. It is advised that feedback about anything is only given to the director. It is rarely appropriate for the monitoring team to ask for someone subordinate to the director to join the meeting, especially if that person is the target of any criticism the monitoring team may want to make. If monitors give feedback, it is important to be clear that they will not identify the individuals who have spoken with the monitoring delegation. It is also important that great care is taken not to say anything that would reveal who had said what.

If monitors have found something particularly dangerous, or consider that a patient/resident is at risk of harm, they could consider disclosing this to the director, and depending on the circumstances, involve the relevant higher authority, eg. regional health authority, or the ministry of health or ministry of social affairs. The monitoring team should tell the director that they intend to do this and give reasons.

### ● Self care

Human rights monitoring is exhausting. It can also be emotionally draining. Human rights monitors will go home at the end of the visit and have a nice dinner and go back to a warm bed in a safe room, knowing that these sorts of comforts may not be available to the many people they have talked to in the institution. Human rights monitoring can be physically exhausting and it is particularly important to watch out that all members of the monitoring team have eaten meals and have drinks and snacks available as needed. It is all too easy to be so engaged as to miss lunch. Low blood sugar levels can cause irritation and decreased attention, so it may be a good idea to carry some small snacks.

It is vital that the monitoring team talks openly about how they are all feeling. If there is a user of mental health services on the monitoring team, it might be difficult to 're-live' experiences by visiting an institution. All members of the monitoring team will need support. This can be very basic such as talking through the difficult issues immediately after leaving the institution. It may mean having an external person available for the monitoring team to talk to. It may mean keeping in touch with each other after the monitoring visits by making the occasional phone call.

## Step 7 Write the report

It may be that the visit took place to one particular institution where the inspectorate was particularly concerned about possible human rights violations, or the monitoring could be part of an ongoing monitoring effort by a national inspectorate body. Whatever the circumstances, analysis and report-writing is a vital part of the monitoring process, and one which is essential to plan. Analysis of the findings of a particular visit may happen informally as monitors discuss among themselves right after the visit their reactions to what they have found during the visit. This can be useful in identifying the key issues on which the report will focus, what sort of recommendations should be made, and the nature of the follow-up. It is also worth arranging a formal debriefing session after each monitoring visit to discuss these points.

Results may reveal problems with the law itself and/or problems with its implementation. Monitors should try to find patterns of problems and systemic issues, rather than presenting a series of individual problems. This analysis can form the basis of the report and its recommendations, because the recommendations need to be based on what was found during the monitoring. During the analysis stage, it is common to realise that further information, interviews or visits are required.

There are various ways of writing a monitoring report. Some monitoring teams write together, and some designate one person to write a draft which is then commented on by the other team members. Whichever strategy is chosen, the writing needs to be done quickly, as the longer the report takes to write and produce, the higher the risk that it will be inaccurate as situations may change. It is advisable for the group to reconvene when there is a near-final text to make any changes and 'adopt' the text formally.

In writing the report(s), gaps in data and interviews may become obvious, and some further data collection may be required. This sort of follow-through can be useful in demonstrating that the findings of the monitoring are right up-to-date. Monitors may wish to send the draft report to the institution for that institution's feedback on facts before it is published.

If the monitoring team is going to translate the report(s), sufficient time must be allocated for translation and careful proofreading.

### ● Content

The report's style will vary according to thematic priorities, and the prevailing style in a particular country. As a good standard for style, monitors are encouraged to read reports issued by the European Committee for the Prevention of Torture<sup>137</sup>. Here are some points to consider about the content of the report:

■ An executive summary, of no more than two pages, can be extremely useful, as it will be the only section that some people read. Monitors should highlight in an executive summary the main issues that have come out of the visits, the methodology of the monitoring visits, and the implications of the findings. All information which appears in the executive summary must be substantiated elsewhere in the report. The executive summary is not the introduction: monitors should get straight to the point.

■ After the executive summary, monitors could think about having an introduction (which explains the context in which the report is written), the main body of the report, and then the conclusions and recommendations. Some reports put the recommendations directly after the executive summary. Another tip is to provide a table of contents with page/paragraph numbers.

■ Sub-headings, bullet points, information in boxes and highlighted quotations are some ways to break the text up and make it easier to read. Appendices can be useful to provide further technical information such as laws or methodological details. A bibliography listing relevant reading may be appropriate.

■ Monitors should be sure that the report contains the date of publication and the contact details of the organisation that carried out the visit(s), and lists the members of the visiting delegation(s). It can be helpful to give some detail on the methodology used. Monitors may want to acknowledge the people who contributed to the report. Where reports are to be put in the public domain, it may be worth stating that the report can be freely disseminated and downloaded so long as the inspectorate body is credited.

■ In the bulk of the report, it is useful to indicate the breadth of your assessment by referring to different sources. The greater number of sources, the more your information is likely to be perceived as reliable. The report should reference previous reports and publications on the topics covered in the report. The report should source directly, which means citing the primary source of information, rather than, for example, referring to journal article that refers to the information.

Monitors should use their judgment to demonstrate patterns and systemic problems. If monitors are unsure about the credibility of a piece of information, it is better to leave it out,

as if one piece of evidence is discredited in a report, this can result in all of the findings being dismissed. It is always worth remembering that all information may be checked.

Information presented should be substantiated, and be backed up with facts. Make information as precise as possible. It is far more impressive to state the exact line of a legal Act, the exact time of an event, or the exact number of people affected. This indicates that an in-depth assessment has been conducted. For example, the sentence: 'Patients in psychiatric hospitals are forced to wear pyjamas' raises more questions than it answers. In which institutions does this happen? On what evidence is this based? Are people forced to wear pyjamas during the day? Are all residents everywhere forced to wear pyjamas?

The report must include technical detail (the wording of laws, for example). An appealing way to present more technical information is to put it into footnotes, endnotes or appendices. In this way, the flow of the report is not interrupted, and details are retained. If precise information is not available, the report could state something like: 'it is not possible to state the exact number of people under guardianship, as no national records are kept by a central authority.'

The report should use quotations, as they add credibility. They show direct contact with people affected by the issue. Quotations can bring dry text to life. Quotations are most powerful when they are used to demonstrate a point. It can be useful to introduce an issue, insert a quotation and then provide a comment. It can be useful to have extended quotations and testimony as they provide human interest. This is sometimes effective at the beginning or end of a section. Source all quotations by detailing the date and place. It may be appropriate (or wildly inappropriate) to identify the interviewee. In circumstances where the interviewee should not be identified – for reasons of confidentiality or protection against retribution – be very sure that the person cannot be identified. In this situation, monitors could use a system of code numberings of interviewees (with records on this kept with the other assessment notes in a secure place). Monitors may want to state in the report that interviewees' identities are not being revealed in order to protect their safety. Due to widespread stigma, it is unfortunately the case that the opinions of people regarded as having mental health disabilities are sometimes seen as non-credible. Therefore when quoting patients/residents it can be useful to have other supporting evidence, or to be quoting from a number of different people.

In order to avoid libellous situations, and to maintain the accuracy and credibility of the report, it is advisable to be cautious when referring to incidents of abuse and violations, by saying, for

<sup>137</sup> All of the CPT's reports are available to download free from their website: [www.cpt.coe.int](http://www.cpt.coe.int) (accessed 19 January 2009)

example: ‘the alleged violation’, ‘it is reported/claimed that...’, or ‘there are unsubstantiated claims that...’

The more objective and balanced a report appears, the more likely that decision-makers, the media, and others to whom the report may be given in different circumstances, will take notice of, and act on it. Thus, the report should distinguish what is factual from what is commentary and analysis or opinion. The report should avoid emotional descriptions (unless these are in a quote) and sensationalist language, as these can reduce the credibility of the monitoring. The report should avoid jargon, and explain any technical terms used. The report should keep TLAs to a minimum (TLAs are ‘three letter acronyms’) The report can provide a list of acronyms at the beginning or end.

Finally, it is advisable to leave some information out. It is usually not possible to include all the information and material gathered. Any material not used may be useful in future monitorings, reports, or media features.

When carrying out independent monitoring, monitors may decide not to publish some information as, for example, there may be times when monitors suspect the person who divulged a particular piece of information is at serious risk of retribution or punishment if the piece of information is published. There may be times when monitors simply lack enough evidence to include an allegation in a report.

## Step 8 Disseminate the report

The monitoring team may consider that their report stands more chance of being taken seriously if the stakeholders to whom the report will be sent are targeted appropriately. The purpose of monitoring places of detention is that ill-treatment is prevented. This means that action must be taken by people in positions of authority to implement recommendations and make changes. Therefore the monitoring team needs to think carefully about to whom the resultant report(s) should be sent. For inspectorates established by law, the primary audience may be specified in legislation, and could be, for example, the national parliament.

Once the report is published, it needs to be disseminated to relevant authorities, organisations and individuals. In order to do this, the inspectorate body needs to compile a list of recipients and get their contact details. When sending out the report, it is advisable to write a covering letter with some key points which will encourage the recipient to read the report. Stakeholders to whom reports may be sent include the following:

- **Governmental authorities**

By the ‘authorities’, we mean top governmental officials such as ministers, policy-makers in ministries and quasi-governmental bodies, right down to the staff of the institutions monitored. Government officials often have limited time and therefore read only executive summaries and recommendations of reports, another reason why monitors should phrase the report’s main findings and conclusions in a succinct manner. Other parts of the report must however be more detailed.

- **Parliamentarians**

Members of parliament may be interested in receiving reports, especially if they serve on relevant parliamentary committees, or have shown a prior interest in human rights issues, mental health issues, or disability issues. Local parliamentarians may also be interested in receiving copies of the report, especially if local government is responsible for running any of the mental health or social care institutions visited.

- **Intergovernmental bodies**

National human rights issues are often of international concern. Monitors should consider sending copies of their reports to the relevant people and bodies within intergovernmental bodies such as the United Nations, or regional organisations such as the Council of Europe, the European Union or African Union.

- **Service users and families**

Organisations of and for people with mental health disabilities and intellectual disabilities may well be interested in the results of independent monitoring of mental health and social care institutions. The monitoring team could gather the contact details of these groups and ensure that they receive the resultant reports. These organisations may then use the monitoring results in their own advocacy and awareness-raising programmes.

- **Service providers**

This group may include different types of mental health or intellectual disability service providers (public and private), professional bodies (for example of psychiatrists, general doctors, nurses, lawyers), complaints bodies and advocacy services.

### ● Media

Monitors may consider that sending copies of the report to media outlets would raise awareness of the issues to the general public. National inspectorate bodies may well have a press officer, and non-governmental organisations may have experience of interacting with journalists – if the monitoring team lacks this experience, it is advised that they contact organisations that have experience in this area. The monitoring team may like to suggest to journalists that they link the ‘story’ to a recent or upcoming event or international ‘day’, for example World Mental Health Day (10 October), International Day of People with Disabilities (3 December) or International Human Rights Day (10 December).

### ● National Human Rights Structures

The monitoring visits may of course have been carried out by a national human rights institution or an ombudsman office. However, if the monitoring has not been carried out by these bodies, the monitors should be sure to send copies of the reports to them.

### ● Academics

Academics and university departments, especially those relating to human rights or social and health care, should also be on the list of recipients, as they can then carry out follow up research, or write about these issues in academic publications.

## Step 10 Plan future visits

Throughout this Toolkit, emphasis has been placed on human rights monitoring being a process that needs to happen on a regular and ongoing basis. Regular monitoring is a way to document human rights progress (or the lack of it) over time and, as OPCAT says, to prevent torture and other cruel, inhuman or degrading treatment or punishment. In planning future visits, the evaluation process in Step 9 should be borne in mind, as improvements will continuously be made. There will always be challenges, but consistency and courage have resulted in significant change. Good luck.

## Step 9 Evaluate the process

The penultimate stage of the monitoring process is to conduct an evaluation. There are many ways that this can be done, but it generally requires gathering different people’s opinions on:

- to what extent the monitoring objectives were achieved.
- to what extent was the monitoring effective.
- to what extent was the monitoring efficient.
- what could be done differently during the next monitoring cycle.

Again, depending on the intended audience and outcome of the monitoring, it is worth considering these points in regards to the impact of the project, the methodology used, the report produced, the distribution and publicity, the management of the project, and the practicalities and logistics. There are many resources available on evaluation.

## 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.

## Section 9 Prompt questions for the monitoring visit (30 Parts)

### Part 1 Monitoring description

- Name, address, telephone number of institution
  - Name of director
  - email of the director
- 
- Type of institution  
(ie hospital, social care home, psychiatric institution)
- 
- Date(s) of monitoring visit
- 
- Monitoring team members

### Part 2 Institution details

#### 2.1 Location (Source: observation)

- Describe the location of the institution.
- Is it located in a rural or urban setting?
- How accessible is it by public transport?
- How far is it from the nearest town?
- Are there gates, or can you/visitors/residents walk in and out  
(refer here to legally voluntary residents?)
- Is there a guard/visitor check-in and check out system?

#### 2.2 Institution (Source: director and documentation)

- How is the institution financed?  
(eg. what per cent by a ministry, local government, residents, private individuals, local community, church, etc) and what is the approximate total budget?
- Is the budget and expenditure publicly available?
- Have the human rights of the people in this institution been monitored (give details)?

#### 2.3 Residents

(Sources: residents, staff, observation)

- How many beds/places are there in the institution?
- How many people are sleeping in this unit/institution tonight?
- Approximate per cent of men and of women?
- Approximate per cent of those aged (a) under 18, (b) 18-65, (c) over 65?
- Most people in this unit/institution are in which of the following categories:  
(1) people with a mental health diagnosis  
(2) people with an intellectual disability diagnosis  
(3) people with a substance or alcohol abuse diagnosis  
(4) people with a neurodegenerative diagnosis (eg Alzheimer's or dementia)?
- About what per cent of the residents are deprived or restricted of legal capacity (under guardianship)?
- Who are the guardians? (eg family members, professional staff, the director of the institution)
- What is the average length of stay in this unit/institution?

- In the last 12 months, how many people left (were discharged):
  - (1) into the community
  - (2) into other institutions
- How many people died?
- What were the ages of those who died in the last 12 months?
- What is the procedure for investigating a death?

#### **2.4 Staff** *(Sources: director and documentation)*

- What is the total number of staff who work in this unit/institution? (full-time equivalent staff numbers)
- How many of the staff are:
  - Psychiatrists
  - Non-psychiatric doctors
  - Qualified nursing and allied staff
  - Non-qualified nurses
  - Psychologists

#### **2.5 Staff training**

*(Sources: staff and documentation, policies)*

- Are staff members required to participate in continuing professional development? (give details)

#### **2.6 Complaints mechanisms**

*(Sources: director, residents, observation, documentation, complaints register, annual report)*

- How do residents make complaints about any aspect of the institution?
- Do residents know about the process?
- Are the residents provided with the necessary means to complain? (eg pens, paper, secure boxes)?
- Are records kept about complaints?
- Is there an annual report published and reviewed about complaints?
- What are the steps taken to deal with unresolved complaints and is there any system of advocacy?

## **Part 3 Living Standards and Conditions**

### **3.1 Material and physical conditions**

*(Sources: director, staff, residents, observation in different rooms (bedrooms, dining rooms, therapy rooms, WC, bathrooms))*

- Is the provision of electricity adequate?
- Is the heating adequate?
- Are there damaged features, such as broken windows, damaged walls?
- Are the parts of the institution to which residents have access adequately clean?

### **3.2 Facilities**

*(Sources: staff, residents, observation)*

- Are the facilities generally overcrowded? (give details)
- Is there adequate access to outdoor areas?
- Are all facilities accessible for people with physical and sensory disabilities?
- Is there an adequate provision of separate areas for men and women?

**3.3 Dining and food**

(Sources: residents, staff, observation  
of kitchen, of dining areas during meal)

- Describe the dining room: is there adequate space for people to eat?
- Is the food nutritious?
- Is the food generally attractive?
- Is there any evidence of malnutrition among residents? (give details)
- To what extent do residents have access to additional snacks and meals?

**3.4 Water** (Sources: staff, observation, residents)

- Is clean drinking water freely available all day to all residents?

**3.5 Clothing**

(Sources: staff, observation, residents)

- Can residents wear clothing of their choice? (is the clothing their own? Do they have to wear uniforms/pyjamas?)
- How are clothes cleaned and how often?

**3.6 Bedrooms**

(Sources: residents, documentation, observation.  
Visit different rooms in different units and collect the information below on a number of different arrangements)

- How many beds in each bedroom?
- Are beds shared? (Can residents choose whom they share a room with or are they forced to share space with others? give details)
- What is the state and comfort of the beds? (if residents give permission, lie on the beds)
- Are there enough sheets and blankets of sufficient quality and cleanliness?
- Do residents have personal objects and pictures around their bed?
- Is there secure space for each resident to keep personal items? (for example in lockers or bedside cabinets)

**3.7 Lighting**

(Sources: observation and residents)

- Are places to which people have access supplied with adequate light?

**3.8 Fresh air**

(Sources: observation and residents)

- Is the air fresh (give details)?

**3.9 Hygiene**

(Sources: staff, residents, observation)

- Are washing facilities freely available?
- Do staff use the same toilets as residents?
- Privacy - are there appropriately separate facilities for men and women? Are toilets and showers etc separated?
- Do they have doors or are they communal? Are they clean?
- Is toilet paper available in sufficient amounts?
- To what extent are residents watched by staff while using bathrooms or toilets?
- Are necessary hygiene supplies for female residents, such as sanitary towels, available?

#### **Part 4 Involuntary commitment and review procedures**

**NB This Part may not be relevant to all institutions**

*(Sources: residents, law, staff, documentation – court or hospital records)*

- Are the appropriate legal procedures for involuntary detention fully implemented?
- Are legally detained residents routinely and fully informed about their rights, including the right to appeal against detention?
- What access is there to assistance and legal representation in relation to involuntary detention?

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

*(Sources: staff, residents, documentation – individual discharge plans)*

- How does support and recovery continue after this period of institutional treatment?
- Who participates in providing support for recovery?
- Who would you like to involve in the support?
- What alternatives to this institution exist in the local area?
- What arrangements does the institution make to discharge the person into community settings?
- Who is responsible for this?

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

*(Sources: staff, residents, observation, documentation – eg weekly schedule, posters etc)*

- How much access is there to newspapers, magazines, books, radio, television, audio books, computers?
- What sorts of cultural, recreational, leisure and sports activities are available to residents inside this unit/institution?
- What sorts of cultural, recreational, leisure and sports activities are available to residents outside this unit/institution?
- Are any residents not allowed to participate in any of the activities? Why not?
- How accessible are these activities for residents?

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

*(Sources: staff and residents)*

- How do people exercise their right to vote?
- Do people receive assistance in exercising their right to vote? (give details)
- Is anyone excluded from voting? (give details)
- Is there any evidence of interference with the process of voting?

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

*(Sources: staff and residents)*

- What types of education programmes are available in the institution and/or in the community? (eg university, high school equivalents, training programmes, vocational education etc)
- What per cent of residents participate in the programmes?

- Are residents used as unpaid staff in the institution?
- Are residents allowed to work outside of the institution?
- Are they paid equally to others in the community?
- How do residents find a job? Explain the process.

## Part 9 Freedom of religion

*(Sources: staff, residents and observation)*

- What accessible opportunities do people have for religious worship of their choice? (inside and outside the institution)
- Describe any obligatory religious practices (give details)

## Part 10 Correspondence and visitors

*(Sources: staff and residents)*

- Is it possible for residents to correspond in private with anyone, via postal letters, telephone or email without any limitations or restrictions?
- Can residents freely access the telephone in private?
- Are personal mobile phones allowed?
- How do residents access the internet?
- Can they do this in private?
- Do staff ever read incoming or outgoing mail? Why?
- Do staff encourage residents to keep contact with people living outside the institution? How?
- How do staff provide residents with assistance, if required, to use the telephone or the internet, or to write letters?
- Are visitors unreasonably restricted in the hours they can visit? Can children visit and what provision is made for this?
- What facilities are there to meet with visitors in a private place?
- Is anyone restricted from having visitors? On what grounds?

## Part 11 Family and privacy rights

*(Sources: staff and residents)*

Introductory question:

- Do you have possibilities for privacy and private life? (living conditions, sexuality, personal hygiene)

### 11.1 Marriage

- Can people get married?

### 11.2 Contraception

- Are choices in forms of contraception freely available?
- Are any residents given contraceptives (eg the pill or depot) without consent?
- Are the side effects of contraception discussed when seeking consent for such treatment?

### 11.3 Pregnancy and parenting

- Are women residents here allowed to become pregnant?
- How many residents became pregnant in the last 12 months?

- How does the institution respond to pregnancies?
- What kind of parenting support is available?
- Is it possible for the parent(s) and the child to stay together?

#### 11.4 Abortion

- When was the last time a resident here had an abortion?
- Who decides that an abortion should occur?
- Can this decision be appealed? (give details)
- Who is informed about the initiation of carrying out an abortion? (looking for them to answer that spouse/family/relatives are informed; this is a very serious procedure)
- What are the procedures for informed consent?
- What information is given to the resident about abortion?
- Are abortions ever performed without the consent of the resident? (give details)
- What support is given to the resident before and after an abortion?
- If there is a resident who has had an abortion, the monitor might speak to her about the entire process (decision-making, consent, outcome/ complications) if she agrees

#### 11.5 Sterilisation

- What are the procedures for free and informed consent?
- What information is given to the resident about the sterilisation?
- Who decides that sterilisation should occur?
- Can this decision be appealed? (give details)
- Who is informed about the initiation of the sterilisation? (looking for them to answer that spouse/family/ relatives are informed; this is a very serious procedure)
- Are sterilisations performed without the informed consent of the resident?
- What support is given to the resident before and after the procedure?

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

*(Sources: staff and residents)*

- Can residents freely express their opinions, raise questions and complaints without negative consequences from the staff?
- How do residents receive information on important issues such as the rules of the institution, their rights, or on advocacy/ self-help groups?
- Is information provided relevant and understandable and in the languages of the residents?

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

*(Sources: staff, residents, documentation)*

- Is there any evidence of torture, ill-treatment, abuse or neglect?
- Have residents made allegations of being mis-treated, abused or neglected? (give details)
- How have such allegations been responded to?

**Part  
14****Restraint and seclusion**

*(Sources: staff, residents, documentation and observation)*

- What types of restraint are used? (eg handcuffs, leather straps, cage beds, or medication)
- Is seclusion used? If yes, see the seclusion room. Take note on size, location, availability of facilities, including toilets, window, overall condition, ability to contact staff in case of emergency
- Under what circumstances is restraint/seclusion used?
- How often is restraint/seclusion used and for how long?
- What is the longest time someone has been put in seclusion or restraint in the past year?
- Who authorises restraint/seclusion and under what circumstances?
- How is use of restraint/seclusion reviewed and terminated?
- Are residents allowed out of restraint/seclusion for the toilet or at other times?
- What human contact do people in restraint/seclusion or seclusion have?
- Is restraint/seclusion ever used as punishment?
- How is use of seclusion recorded?
- Is seclusion or restraint used because of insufficient human resources/staff?
- Is there any regular external inspection of restraint/seclusion policies and practices?

**Part  
15****Habilitation and rehabilitation**

*(Sources: staff, residents, documentation)*

Introductory question:

- Are you allowed to take responsibility for yourself and to do meaningful things? (eg everyday tasks, hobbies, studies)
- What therapeutic and re/habilitative activities are available? (eg these may include creative activities such as art or music therapy, or may include occupational therapy and opportunities to learn new skills)
- What choice do residents have about which activity they would like to do?
- Are these meaningful and enjoyable activities or merely repetitive and boring tasks?
- Are any forms of peer support available?

**Part  
16****Consent to treatment**

*(Sources: staff, residents, documentation)*

- What is the procedure used in this unit/institution to gain informed consent to treatment?
- Describe what the institution understands as consent to treatment
- What happens if the resident refuses treatment? (does the institution respect the decision, can such decisions be ignored, and under what circumstances?)
- Can treatment ever be imposed? (give details)
- How can a resident appeal against a decision to treat without consent?
- Are involuntary treatment orders reviewed systematically by an independent body?

**Part 17** **Access to physical health care**

*(Sources: residents and staff)*

- Are there any difficulties in getting physical health care for those who require it?
- What have been the most important physical health problems in the last year?
- Do residents have access to regular physical health care check ups?
- What happens when residents need specialised physical healthcare assistance?
- Who pays for physical health care costs?
- What expenses must the residents cover and is this affordable?
- What happens to residents who can't cover these expenses?
- Are there other barriers to accessing physical healthcare?

**Part 18** **Access to mental health services**

*(Sources: residents and staff)*

- Can residents see a psychiatrist or other mental health professional when they want?
- How often does a resident usually meet with a psychiatrist or mental health professional?
- About how many hours each week is there a psychiatrist or mental health professional present in this unit?
- Do residents have a choice of psychiatrist or mental health professional?
- How long does a meeting with a psychiatrist or mental health professional usually last?
- Are these meetings in private?
- What types of assessment and treatment are available in a mental health crisis?

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

*(Sources: residents and staff)*

- Can residents see a general practitioner of their choice when they need?
- What sort of training does the general practitioner have in dealing with the health care needs of people with mental health problems?
- What sort of training does the general practitioner have in dealing with the health care needs of people with intellectual disabilities?

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

*(Sources: residents and staff)*

- Can residents see a nurse or member of the care staff when they want?
- Do nurses and care staff have specialist training in mental health care?
- What is the general quality of care given by nurses and care staff?
- How therapeutic and person-centred are the attitudes of the nurses and care staff?
- About how many hours each week is there a qualified nurse present in this unit?

## Part 21 Access to therapies

(Sources: residents and staff)

- Can residents see a psychological therapist?
- Can residents see a psychological therapist of their choice?
- Can residents see a social worker/social therapist of their choice?
- Can residents see an occupational therapist of their choice?

## Part 22 Health records

(Sources: residents, staff, documentation)

- Are case notes comprehensive, ordered and intelligible?
- Are they appropriately confidential?
- Are case records freely available to those who need to access them, including residents?

## Part 23 Physical health promotion and physical illness prevention

(Sources: residents, staff, documentation)

- Do residents have access to the appropriate quality of health promotion and illness prevention services, taking into account the high levels of physical illness among people with mental health problems (eg vaccinations, diabetes checks, mammograms)?
- Are residents weighed on admission and regularly thereafter?
- Are there accessible facilities for physical exercise?
- Are there barriers to using such facilities?
- Do regular physical health checks take place to detect cancer?

## Part 24 Medication for mental and physical conditions

(Sources: residents, staff, documentation)

- Are prescribed medications regularly available and affordable to residents?
- Are medications administered in accordance with agreed clinical practice guidelines?
- Are medications stored appropriately?
- Are side effects reported by residents taken seriously by staff and acted upon?
- Are resident preferences for medication acted upon by staff (eg for route of administration)?
- Is there any evidence of over-medication of residents to ease management of the institution rather than for an individual's personal benefit? (eg observe physical side effects of some medications – are people drowsy drooling, unable to communicate, shuffling)
- Is there any evidence that staff on duty are given too much discretion in using medication? (eg in the use of sedating 'as required' medications)
- What happens when a resident does not want to take their medication?
- Is there a written record of residents' treatment and dosages?
- Is the dosage appropriate to the clinical condition and not given for the convenience of staff or for punishment of the residents?

## Part 25 Physical health assessment on admission

(Sources: residents, staff, documentation)

Introductory question:

- Was your physical health condition examined when you came here?
- Is a resident's physical health assessment routinely undertaken upon admission and on the basis of informed consent?
- Who performs this assessment?
- Are the findings of the assessment and any treatment implications clearly explained to the resident?
- Is this medical assessment performed with due respect to gender, cultural and religious background?
- What happens if a resident refuses the examination?

## Part 26 Diagnosis (physical and mental)

(Sources: residents, staff, documentation)

- Do qualified practitioners undertake an assessment leading to a physical health diagnosis?
- Do qualified practitioners undertake an assessment leading to a mental health diagnosis?

## Part 27 Electro-Convulsive Therapy (ECT)

(Sources: residents, staff, documentation)

- Is ECT given in the institution? If so, for what reasons?
- Is ECT ever given without sedation/anaesthesia/muscle relaxants?
- Are the details of each ECT treatment recorded?
- What side effects are reported?
- Is ECT used in a way that is perceived by residents as a form of punishment?
- What happens if a resident refuses ECT?

## Part 28 Alcohol, cigarettes and illegal drugs

(Sources: residents, staff, documentation)

- Is alcohol available to residents on the same basis as in the local community?
- Are cigarettes available to residents on the same basis as in the local community?
- Is attention paid by staff to the use of illegal drugs by residents?
- What types of assistance/support is available for residents with:
  - 1 Alcohol problems?
  - 2 Smoking problems?
  - 3 Drug problems?

## Part 29 Involvement in care plans

(Sources: residents, staff, documentation)

Introductory question:

- How have you participated in the decision-making and plans regarding your treatment and rehabilitation?
- Does each resident have his/her own care plan?
- How involved are residents in forming their care plans?

- Can residents question and challenge the content of their care plans?
- Do care plans specify individualised medication and therapeutic arrangements?
- How often are plans reviewed?
- Are care plans made available in languages understandable to residents?

**Part  
30****Consent to participate in research**

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*(Sources: residents, staff, documentation)*

- Is there a written consent process to participate in research?
- Is there an independent process of ethical approval for research projects?
- Do potential participants have enough information to make an informed choice?
- Is research carried out on people who are legally detained?
- Is research carried out on people who do not have the capacity to consent?
- If medical research is being conducted in the institution on people who are detained, or do not have the capacity to consent, who has been informed of the research?
- Is payment being received?
- Are there any restrictions on accessing usual care for residents who do not agree to participate in research?