Module 9

From exclusion to inclusion: rights in the community

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1. Overall Learning Aim

The aim of this module is to enable students to understand the role of international human rights law, and national legislation and policy in promoting the rights and equality of persons with mental health disabilities in the community.

It should at this stage of the course be apparent that the welfare and well-being of people with mental health disabilities is not solely dependent on (and for some people not dependent on at all) medical care and treatment. On the contrary, other areas of life significantly impact upon the rights of people labelled with mental health disabilities, and consequently their daily lives. Such areas of life include someone's family circumstances, housing, work and the extent to which they feel like society is treating them as equals and respecting their decisions. We therefore need to look into areas of law other than (mental) health law, in order to identify relevant issues and understand how legislative and policy reform is necessary to minimise discrimination in all aspects of someone's life so that a person with disabilities may enjoy the full range of human rights on an equal basis with others. In removing the legal barriers to full participation in society, we can go some way towards removing the pervasive environmental and attitudinal barriers which often prevent people with mental disabilities from fully enjoying the right to live in the community.

Even where the right to live in the community is enshrined in law and respected in practice, people with mental health disabilities often face stigma by the population generally, and discrimination in specific areas of life. This module outlines international human rights law which protects against discriminatory denial of civil, political, economic, social and cultural rights to which people with mental health disabilities are subject.

The module encourages critical examination of a range of laws other than 'mental health laws'. The reason for this is that areas other than classic mental health law may have an impact – positive or negative – on the lives of people with mental health disabilities. Such laws may be in the field of: family law, employment law, education law, civil law, civil procedure law, electoral law, housing law, social security law, criminal law, criminal procedure law, and administrative/public law. In some countries there are additional human rights or equality laws. The module asks students to look across these legislative areas and consider action which may be needed to ensure that domestic laws are brought into compliance with international human rights law and standards and to ensure that these domestic laws are monitored and implemented.

2. Contents of the Module

1. Right to live in the community

As students will by this stage of the diploma be aware, the UN Convention on the Rights of Persons with Disabilities (hereinafter "CRPD") has a stated purpose to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."[1] As discussed in other modules of the course, people with disabilities have been (and in some countries still are) segregated and isolated in large and often remote long stay residential institutions. In some countries including a number of European countries, Canada, USA, Australia and New Zealand, there has for several decades been an acknowledgment that such institutionalisation is not appropriate.

Total institutions

The sociologist Erwin Goffman coined the phrase "total institution". By this he meant a places of residence and work where a large number of like-situated individuals, cut-off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life (Goffman, 1961). The main feature of total institutions is a breakdown of the barriers ordinarily separating where we sleep, play and work. Total institutions are places where:

All aspects of life are conducted in the same place and under the same central authority.
Each phase of the member's daily activity is carried on in the immediate company of a large group of other people, all of whom are treated alike and are required to do the same thing together.
All phases of the day's activities are tightly scheduled, with one activity leading at prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials.
The various enforced activities are brought together into a collectively regimented single rational plan purportedly designed to fulfil the official aims of the institution.

As noted, in several countries reforms have taken place to gradually close large residential institutions and replace them with a range of more appropriate, smaller, community-based services. The main reason why these reforms have taken place and continue to do so is because there is a growing recognition that such institutions are associated with wide ranging human rights violations and are not conducive to the wellbeing and recovery o people being detained within them.

Institutions limit human rights in several ways. They impact on a person's right to a private life, they limit a person's right to family life, they may override a person's competent refusal to accept mental health treatment thus violating the right to be free from torture, inhuman, cruel and degrading treatment. Institutions may additionally restrict the inmate's right to associate, and the right to thought, conscience and religion. The inmates of institutions are in many countries automatically deprived of their legal capacity, and may therefore be automatically barred from the right to vote, to work, to

[1] CRPD, Art. 1.

marry and found a family, and to decide where to live. These provisions explicitly violate fundamental rights outlined in both the International Covenant on Civil and Political Rights, and the International Covenant on Economic, Social and Cultural Rights. We will return to these in this module.

Living in the community as an enforceable human right

It has long been argued by reform-minded lawyers that institutionalisation as such is a violation of the right to privacy, of freedom from torture, cruel, inhuman and degrading treatment and punishment, and of the right to non-discrimination. Indeed there may be domestic provisions which provide the right specifically. However, for the first time in international law, Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) expressly establishes the right for persons with disabilities to live in the community as a human right. In the same Article, the CRPD establishes obligations on States to ensure that people with disabilities:

- May choose their place of residence (Article 19(a)).
- May choose with whom to live (Article 19(a)).
- Have access to specialised community-based support services (Article 19(b)).
- Have access to services which are available to the general population (Article 19(c)).

Article 19 establishes an unequivocal right for people with mental health disabilities to live in the community. Article 19 lists no exceptions, which means that everyone is entitled to the protection of Article 19, regardless of a country's resources, regardless of the individual's level of disability and degree of support needs, or geographic location.

Disability rights activists have advocated for an Article 19 type provision for many years. The resultant CRPD goes further than international standards before it. For example, principle 3 of the UN's "Principles for the protection of persons with mental illness and the improvement of mental health care" (commonly referred to as the "MI Principles"), states, "Every person with a mental illness shall have the right to live and work, *as far as possible*, in the community" (emphasis added). [2] The CRPD contains no equivalent "as far as possible" qualifier, nor does it restrict itself to the living and working in the community, rather Article 19 provides for "full inclusion and participation in the community".[3]

Article 19 contains specific State obligations. In saying that States must ensure that people with disabilities may choose where to live and with whom to live, there is an obligation on States to change domestic laws to facilitate this to happen. In many States where people with disabilities are segregated in institutions, law provides no right to live in the community, and there is no legal mechanism in domestic legal system to enable an institutionalised person to seek legal assistance, and to seek a judicial remedy to end their institutionalisation and claim compensation. Intimately linked to the phenomena of institutionalisation is the legal structure of "guardianship" which deprives a person of

[2] **"**Principles for the protection of persons with mental illness and the improvement of mental health care**",** Adopted by General Assembly resolution 46/119 of 17 December 1991.

[3] See Parker, C. and Clements, L. (2008) "The UN Convention on the Rights of Persons with Disabilities: a New Right to Independent Living?" *E.H.R.L.R.*, issue 4

legal capacity – an enormous barrier to the right to live in the community, to which we will return in the second section of this module. In several countries an adult's guardian can simply decide to place the adult with disabilities in an institution for the rest of that person's life, and the adult has no recourse to challenge the decision.

It is at this point worth noting that the CRPD contains a specific provision on the right to live in the community for children with disabilities, Article 23 aiming "to prevent concealment, abandonment, neglect and segregation of children with disabilities", and for such children and their families to receive early and comprehensive information, services and support.[4]

Services in the community

The CRPD obliges governments to ensure a sufficient range and quantity of services for people with disabilities in the community.[5] Obliging States to focus on developing community-based services *at the same time as* reducing the numbers of people in institutions is crucial. Theoretically at least this approach will ensure that institutions are closed and that services are available, thus preventing people with disabilities ending up being homeless or in prison. In the United States many previously institutionalised with disabilities did not have the life skills to look after themselves after leaving the community, and insufficient services were provided. They were also not able to earn sufficient income to maintain independent housing (a right to which we will return later in this module).[6] Looking back at the US deinstitutionalisation process, Accordino et al argue that "[i]n retrospect, policymakers, clinicians, and rehabilitation professionals, in their zeal for deinstitutionalizing people with [severe mental illness], may not have grasped the complexities and difficulties that people with [severe mental illness] experience when living in the community".[7] This is not an argument against deinstitutionalisation, but rather a wake-up call to governments to focus their attention on ensuring that people with disabilities have access to appropriate community-based services. Such services might include, for example, personal care assistance, day care centres, meals-on-wheels, occupational therapy, and community mental health nurses.

As well as specifying that a State must provide specific services for people with disabilities in the community, the CRPD goes further and establishes a State obligation to ensure that services and facilities *for the general public* be (a) available to people with disabilities, and (b) be tailored to the needs of people with disabilities.[8] Such services and facilities might include libraries, one-stop-shops for local governmental services, legal advice centres, adult education classes, assistance with finding employment and so on. This provision of the CRPD is mirrored by Article 9 on accessibility, which points

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[4] CRPD, Art. 23(2).
[5] CRPD Art. 19(b).
[6] Feldman, S., "Out of the hospital, onto the streets: the overselling of benevolence", Hastings Center Report, 1983 Jun; 13(3):5-7. See also the following article which is available online and provides a comprehensive story of deinstitutionalisation process in the US. Michael P. Accordino, Dion F. Porter, Torrey Morse, "Deinstitutionalization of Persons with Severe Mental Illness: Context and Consequences", *Journal of Rehabilitation*, April-June, 2001 available online at http://findarticles.com/p/articles/mi_m0825/is_2_67/ai_76398484 (last accessed 1 July 2009).
[7] Accordino et al, *op cit*.
[8] CRPD Article 19(c).

out that all services should be accessible to people with disabilities, to enable them "to live independently and participate fully in all aspects of life".

2. Right to equal recognition before the law

Legal capacity

Of crucial importance if people with mental health disabilities are to be included as equals in society is that the law treats them as such. All over the world it is common that people with mental health disabilities, intellectual disabilities, or other (and no) disabilities can be deprived or restricted of their legal capacity. The policy driver behind such as system is to provide protection against neglect and abuse for vulnerable people, but it is now recognised that this is not an appropriate way to deal with people who may need assistance in making decisions. What is the arrangement in your country?

Under the guardianship paradigm, a judge, on the basis of a medical doctor's opinion, can decide to deprive or restrict a person of their legal capacity. In some countries the case then goes to a local government office which allocates someone to take decisions on behalf of the adult. Such decisions could be, for example, to enter into an employment contract, to decide on medical treatment, to decide on how to use a person's finances, to decide where and with whom to live, to take someone to court, and make other decisions of a legally significant nature. This other person is usually called a 'guardian', and in some jurisdictions a 'trustee' or 'tutor'.

Over the past few years there has been growing concern that the system of guardianship, far from protecting people from exploitation and abuse, is actually a system which facilitates such exploitation and abuse. It was this concern which prompted UN Member States to address the situation in the CRPD. The CRPD aims to remove barriers which hinder people's full and effective participation in society on an equal basis with others, and in addressing legal capacity it is removing a major legal barrier.

Modern human rights law has tried to change this system in two ways. It has firstly tried to make systems better. Why? Because as mentioned there is growing recognition that in many countries, including some 'developed' European states, guardianship serves to facilitate human rights abuses, not prevent them. Additionally activists have highlighted glaring procedural flaws in guardianship systems resulting in violations of the right to fair trial / due process which would never be countenanced in, for example, criminal justice systems. Further, guardianship systems are premised on the medical model of disability in which diagnosis equals inability. As Amita Dhanda has written, "guardianship is unacceptable because it is premised on the incapacity of persons with disability. It is a device by which whilst the life affairs of persons with disability are managed, our rights to growth and development are thwarted".[9]

[9] Address to the plenary session of the ad hoc committee by Amita Dhanda on legal capacity. Available at: http://www.un.org/esa/socdev/enable/rights/art9plenary.htm (last accessed 1 July 2009).

To illustrate how guardianship happens in practice here is a scenario which may read like a fictional plot, but which is common in many countries.[10]

> Lilla, a 24 year old woman has a diagnosis of a mental illness and lives with her father. The father is getting fed up with Lilla's troublesome behaviour, and thinks that Lilla is spending her money on frivolous things. The father wants to have Lilla placed under guardianship so that he can make the decisions for her, and send her to a residential institution to look after her. He pays a psychiatrist to examine Lilla. Lilla does not want this to happen, so the psychiatrist arranges for Lilla to be forcibly taken to a psychiatric hospital and detained for the incapacity assessment. When this happens the psychiatrist does not tell Lilla that he is examining her with a view to her being placed under guardianship. The psychiatrist writes a brief report which goes to the judge. The report contains a recommendation to the judge that Lilla is too mentally ill to attend court.
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> The judge holds a court hearing to decide the case, and the father is present but Lilla is not, because she has not been informed of the court hearing. A local government representative is present but does not say anything. After reading the psychiatrist's report, the judge decides that Lilla probably cannot take decisions by herself, and that her father is much better at taking the correct decisions. The judge makes an order which deprives Lilla's legal capacity and places her under the guardianship of her father.
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> Several weeks later, the father arranges for Lilla to be sent to a social care institution where the visiting doctor decides to increase her anti-psychotic medication. She is not allowed to leave the institution, and is punished when she speaks out of turn. She has no money to spend on anything she wants. A few months later there is a general election, and Lilla is informed that because she has been deprived of her legal capacity, she is not allowed to vote. She wants to find a job, but is told that she cannot leave the institution and that people deprived of their legal capacity are not allowed to work.
>
> She doesn't like any of this, so asks the staff what she can do to change the situation. She is told that she can make a complaint to the director. The director tells her no court or authority will listen to her, because he is the guardian. She, as a person deprived of legal capacity, has no 'legal standing' to complain or bring legal cases – her guardian must make all legal actions on her behalf.

There are of course several human rights issues which we can untangle. We can split them into procedural and substantive issues, and all of these are based on research carried out in several countries by the Mental Disability Advocacy Center from 2006 to 2008. There may be similar issues in your jurisdictions.[11]

Procedure:

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[10] For more information on country-based analysis of guardianship laws and human rights, see the series of reports produced by the NGO Mental Disability Advocacy Center.

[11] See also the European Court of Human Rights case of *Shtukaturov v. Russia*, European Court of Human Rights, Application No. 44009/05, judgment 27 March 2008, which you will read about for the module 10 assignment.

- adults subject to guardianship proceedings are not properly notified of pending court and administrative processes relating to legal capacity.
- adults and their representatives do not have access to information about all proceedings related to the procedure for depriving the person of his or her legal capacity.
- adults are not present and heard at these court proceedings.
- legal representation is not available during all guardianship procedures, including appeals.
- lawyers and judges dealing with these cases have received no training on the practicalities of the guardianship process and on how to represent clients whose functional capacity may be diminished.
- the type and quality of evidence needed for a judicial finding of deprivation of legal capacity is unclear.
- there are no objective criteria for selecting a guardian and clearly prohibiting people who have conflicts with the interests of the subject adult from serving as guardian.
- there are no objective criteria for conducting incapacity assessments, and no obligation that such assessments be made by a multi-disciplinary team (not just a psychiatrist).
- guardianship is viewed as a permanent measure because there is no compulsory review of the necessity of guardianship.
- guardians receive no training on how to carry out their duties, and there is no requirement for continuous professional development of guardians.
- guardians are not required to regularly visit all adults under their care, and to discuss all relevant issues with them. In the event of the adult not being able to express his or her wishes, there is no obligation on guardians to find out about the adult's previously known wishes and make decisions which are in line with the adult's known belief system and life narrative.
- there are no complaints mechanisms at local authorities, which have the responsibility to supervise guardians; and there is no obligation on such authorities to provide information in an understandable format to all adults under guardianship.
- adults under guardianship are prohibited from applying for modification or termination of guardianship.
- adults under guardianship have no right to challenge the appointed guardian.
- there is no effective complaints mechanism for adults under guardianship, including access to judicial remedies.

Substantive issues:

- guardianship is rarely proportional to the support that it allegedly aims to provide.
- adults are detained in order to assess functional incapacity.
- plenary (all encompassing) guardianship exists, which removes an adult's decision-making authority in all legally relevant areas.
- adults under guardianship are automatically deprived from exercising such fundamental rights as the right to work, right to property, right to family life, right to marry, right to vote, and right to associate.
- adults under guardianship are not allowed to decide where to live and with whom to live (see below).

- guardianship is not used as a last resort.

CRPD's paradigm shift

Article 12 obliges countries to make sure that any process related to decision-making has appropriate and effective safeguards to protect against abuse. Such safeguards need, at a minimum to protect against conflicts of interests. In some countries (for example, Russia and Bulgaria),[12] directors of residential institutions are often the guardians of the residents, which means that the resident has no external person to turn to should he or she have a complaint about any aspect of their lives. Another example of a conflict of interest would be where a relative of an adult with mental disabilities applies to place the adult under guardianship in order to access the adult's finances and the court appoints that adult to be the guardian. These are obvious conflicts of interest, and cases need to be decided on its own unique set of facts.

Article 12 specifically mentions safeguards which should be inherent in any system which provides decision-making support to people with disabilities. A primary safeguard is that there should be a regular review of the necessity of the measure. As is explained in module 7 which looks at issues of consent to treatment, functional capacity often changes across time and depending on the circumstances, so it is possible for someone to need support temporarily. This is especially the case for people with cyclical forms of mental illness (such as bipolar affective disorder or some forms of schizophrenia). Some existing guardianship laws allow for no review, so that if a person is placed under guardianship, they are deprived of their legal capacity for life. You will notice that Article 12(4) calls for a review "by a competent, independent and impartial authority or judicial body" – this means that such a review cannot be carried out by, for example, a psychiatrist, or a guardianship office of a local government.

It is the deprivation or restriction of legal capacity which restricts the enjoyment of other rights. For example, in many countries people under guardianship are prohibited from voting, even though the capacity to vote was never considered by the judge which deprived or restricted the adult of legal capacity. Another right which is often removed is the right to property – that is the right to manage, acquire and dispose of money, goods and even housing. Other rights which are often denied people with mental disabilities on the grounds of incapacity include the right to marry and found a family, the right to associate, and the right to work. The subject of legal capacity can therefore be seen as central to critical issues and rights affecting the lives of people with mental disabilities which this module will address.

The Council of Europe has produced guidance as to the minimum standards which guardianship and similar systems should contain, and this document is worth reading, but it must be borne in mind that this document is still within the framework of making systems better.[13] To recap, it has been argued thus far that the first way which human

[12] See *Guardianship and Human Rights in Russia*, Mental Disability Advocacy Center, 2007, p. 38; and *Guardianship and Human Rights in Bulgaria*, Mental Disability Advocacy Center, 2007p. 42.

[13] Committee of Ministers Rec(99)4 on principles concerning the legal protection of incapable adults, 23 February 1999, available here https://wcd.coe.int/ViewDoc.jsp?

rights law has approached the legal capacity issue is to make systems better, that is, to minimise procedural and substantive human rights violations from the process and from the result.

Article 12 CRPD emphasises that any measure should be "proportional and tailored to the person's circumstances", as does the Council of Europe Recommendation, cited in the above paragraph. It is the lack of proportionality of traditional guardianship systems which has prompted international human rights law to call for a paradigm shift away from a removal-of-autonomy model. Thus, the second way that modern human rights law has begun to influence guardianship and legal capacity is not to make systems better, but to make better systems. The new paradigm insists that however much we can adjust a guardianship system to make it *nicer*, guardianship will still remove the adult's right to make autonomous decisions and hands the power to someone else. (A powerful analogy can be drawn with the issue discussed in the section above, 'Total Institution', namely that an institution will always be an institution, however *nice* it may look.) The removal of someone's autonomy is seen as dehumanising, and runs against the grain of the core of the CRPD, which is about providing support, promoting equality, autonomy and self-determination.
It is clear from any reading of the CRPD that stripping legal capacity from an adult with mental disabilities impacts negatively on their autonomy and self-determination. The CRPD deals with this issue in Article 12, which is reproduced in your course materials. In terms of making better systems Article 12 advises that a paradigm shift has two essential elements.

The first element of the shift is that people with disabilities must have and "enjoy" legal capacity on an equal basis with others. In law, to enjoy a right means to exercise that right. This is certainly not the case in many countries. Any country which has a system of guardianship will fail this test, for the simple reason that guardianship means that all or part of an adult's legal capacity has been stripped from that person and handed over to another person (the guardian). It is the guardian who takes all legally binding decisions on behalf of that person, and in many countries the guardian is not obliged to discuss the decision with the adult in question.

The second element of the paradigm shift is that countries must provide support to people with disabilities in decision-making if they need such support. We will explore what this means and how this differs from guardianship.

Planning for functional incapacity in the future

People who have functional capacity are able to plan for future cases of incapacity. This is especially important as the ageing population is growing, and certain dementias (such as Alzheimer's disease) are increasing. Legislation can assist such people by providing legal mechanisms to allow planning for incapacity: advance directives, and powers of attorney.

An advance directive is an instruction given by an individual specifying what should be done in the event of that person's functional incapacity. (Living wills are one type of

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advance directive in which an individual specifies end-of-life decisions in advance). Advance directives are usually formal documents witnessed by another person.

A power of attorney (or enduring or lasting power of attorney) is a document in which the adult appoints an individual or group of individuals to made decisions in the event of that person's incapacity.

However, not everyone is in a position to plan for future incapacity, because they may already require support. This is true for many people with intellectual disabilities, who have had their disabilities from birth. It may also be true for some people labelled with mental illness who are in a period off mental ill-health. In such cases, as discussed in Module 7, the CRPD offers a new paradigm for providing support. Instead of guardianship which, as we have seen, removes someone's power to make legally binding decisions, the CRPD proposes supported decision-making.

Supported decision-making

The concept of supported decision-making is simple. An adult has a group of people around him/her who support the adult in making decisions. Michael Bach of the Canadian Center for Community Living has defined supported decision-making as "an accommodation in legally-regulated decision-making processes to protect the right to exercise self-determination for those vulnerable to losing this right." Supported decision-making "provides legal recognition and status to trusted others (sometimes called "associates") to assist in any aspect of protecting the personhood of an individual".[14]

Supported decision-making is not a new concept. It is a concept by which most of us make major decisions, and we deploy the concept without thinking about it. Probably few students decided to enrol on this diploma without consulting someone, probably few have bought a house, car or pet without consultation.

Several provinces of Canada have undergone legislative reforms and introduced supported decision-making models. "Plan" is a Canadian NGO which provides supported decision-making services. Their website says:

"Families walk a balancing act between respecting choices and ensuring the safety and well-being of our family members. This balancing act often finds families erring on the side of safety and caution. Ensuring choice for our relatives is both a stress as some control is released, as well as freedom for families and individuals as they begin to explore decision making. For our relatives to become good at making the decisions in their lives, they need to:

- Be respected for their inherent decision-making abilities
- Develop authentic decision-making voices
- Receive support where necessary
- Have genuine choices and options
- Make decisions based on those choices

[14] Taken from a PowerPoint presentation downloadable here www.un.org/esa/socdev/enable/rights/ahc7docs/ahc7ii3.ppt (last accessed 1 July 2009).

- Have alternatives to legal guardianship
- Be able to make mistakes". [15]

Supported decision-making systems recognise the natural inter-dependence of human beings and often adhere to the following principles:

- the adult retains full legal capacity whilst receiving services from a support person/network;
- a support person/network should not be appointed without the adult's consent;
- there must be a relation of trust between the adult and the supporting person/network;
- a court should therefore not create such relationship, only recognise its existence
- the support person/network should not act on behalf of the adult. This role is limited to merely providing the adult with support and assistance in making and communicating decisions.
- there must be safeguards in place to protect the adult against abuse and exploitation.[16]

An easy-to-read guide for adults in the Canadian province of Yukon provides a useful checklist of what supporters do and what they don't. Yukon calls these supporters "associates", and in that province:

The associate:

- helps get information you need to make a decision;
- explains the information, as well as choices you have;
- helps you sort through the choices and come to a decision;
- helps you communicate your wishes; and
- helps you put your decision into action.

The associate cannot:

- make decisions for you;
- do things without you knowing;
- get information about you without you knowing and agreeing; or
- talk about you with other people without your permission.[17]

For more information about moving away from guardianship models and towards supported decision-making models, see the UN Handbook for Parliamentarians on the CRPD.[18] Several Canadian organisations deliver supported decision-making services and information is available on their websites.[19] You can also read interventions on supported decision-making made to the UN ad hoc committee which developed the

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[15] See http://www.plan.ca/Programs_Decisions.php (last accessed 1 July 2009).
[16] Taken from MDAC's reports on guardianship and human rights, op cit.
[17] "Supported Decision-Making Agreements: could this help me?" Downloadable brochure http://www.hss.gov.yk.ca/downloads/supported_dm_booklet.pdf (last accessed 1 July 2009).
[18] Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities, available at http://www.un.org/disabilities/default.asp?id=242 (last accessed 1 July 2009).
[19] See for example, Nidus Personal Planning Resource Centre and Registry http://www.rarc.ca, Canadian Association for Community Living http://www.cacl.ca (last accessed 1 July 2009).

CRPD.[20] Further, there are a small number of academic journal articles dealing with the subject.[21]

3. Right to access to justice

Casting doubt on credibility

People with mental health disabilities are often viewed by the justice system as non-credible victims and witnesses. The person's mental illness is seen by the system to cloud the person's judgment, and lawyers will try to poke holes in a person's testimony, casting doubt on their ability to tell the truth and remember accurately. As an example, the NGO Mental Disability Advocacy Center is currently litigating a case before the European Court of Human Rights in which the applicant is a woman who alleges she was raped by a male nurse while she was an in-patient in a psychiatric hospital. On learning of her allegation, the hospital did nothing. Some time later, police and prosecutors failed to properly investigate the allegation. The applicant is alleging that this non-investigation was itself a violation of her human rights, and that the authorities decided not to investigate on the basis of disability discrimination.[22]

In countries which have jury systems, people with mental health disabilities are further excluded from serving on a jury. As one journalist with a mental illness has written, "I might come to court as a victim of crime, or be called as a witness, but in both situations my mental health history will almost certainly be used to discredit my evidence. And I could, of course, stand in the dock myself, to be tried before a jury of my fellow citizens - fellow except that, by definition, none will have shared my experience".[23]

Equality standards

The CRPD obliges countries to "ensure effective access to justice for persons with disabilities on an equal basis with others" so that they can be an effective participant in whatever role they find themselves.[24] The CRPD says that for this to happen, staff

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[20] See, for example, the intervention on behalf of the International Disability Caucus, made by Amita Dhanda, op cit.

[21] See, for example, Robert M. Gordon (2000) "The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making" 23(1), *International Journal of Law and Psychiatry*, January-February, pp. 61-77. and Amita Dhanda (2007) "Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?" 34 (Vol. 2) Syracuse J. Int'l L. & Com. *Symposium: The United Nations Convention on the Rights of Persons with Disabilities*, pp. 429-462.

[22] Author's personal knowledge. No reference is given as the case is pending.

[23] "The jury's out: I'm guilty of having a mental illness", Clair Allen, The Guardian, March 7, 2007. Available online at http://www.guardian.co.uk/society/2007/mar/07/socialcare.guardiansocietysupplement1 (last accessed 1 July 2009).

[24] CRPD, Art. 13(1).

working in the administration of justice (court, prison, police, probation staff) should receive appropriate training.[25]

4. Right to adequate standard of living and social protection

In addition to a range of support services (which may include community psychiatric nurses, occupational therapists and social workers) the housing of people with mental disabilities is of crucial importance. If institutions are to be closed, alternative housing must be provided. Such housing would include a range of housing such as halfway homes, crisis centres, long-stay supported homes, as well as regular public housing.

Right to housing

Lack of access to housing for people with mental disability is also a serious problem which often leads to homelessness. A WHO report highlights a some studies reflecting this.[26] In the US for example, a person with a mental health condition is seven times more likely to become homeless than the general population. [27,28] In China a 10 year follow up of a cohort of people with schizophrenia found that 7.8% had experienced homelessness while the rate of homelessness during the 10 year period was 0.9 per 100.[29] In Nigeria at a 13 year follow-up of "clinically stable outpatients" it was found that 4% were homeless or lived in an unstable setting.[30]

The right to adequate housing is contained in several international human rights treaties.[31] All of these provisions were examined when the CRPD was drafted, and Article 28 of the CRPD provides a comprehensive list of the elements for an adequate standard of living and social protection. These elements include food, clothing and housing (the latter of course must be cross referenced with the right to live in the community which we addressed earlier in the module). The CRPD is the first human rights treaty to include the right to clean water. It also refers to poverty reduction programmes, and advocates for access to social protection for vulnerable groups such as women and girls with disabilities, and elderly people – including access to retirement benefits and programmes.

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[25] CRPD, Art. 13(2).

[26] "Vulnerable groups in development: the case for targeting mental disability", WHO, Geneva 2009 (forthcoming).

[27] Prevalence of homelessness in a US study (www.uphs.upenn.edu/cmhpsr/hdug/esprev.doc) in general population: no more than 2% (in the worst district but estimated 15% for people with mental disorders in some other studies).

[28] Folsom DP et al. Prevalence and risk factors for homelessness and utilization of mental health services among 10,340 patients with serious mental illness in a large public mental health system. *American Journal of Psychiatry*, 2005, 162(2):370-376.

[29] Ran MS et al. Homelessness among patients with schizophrenia in rural China: a 10-year cohort study. *Acta Psychiatrica Scandinavica*, 2006, 114(2):118-123.

[30] Gureje O, Bamidele R. Thirteen-year social outcome among Nigerian outpatients with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, 1999, 34(3):147-151.

[31] See, for example Art. 11(1) ICCPR, Art. 14(2) CEDAW and Art. 27(3) CRC.

Importantly, the CRPD calls for inclusion of people with (mental) disabilities in public housing programmes.[32] This echoes WHO recommendations that housing legislation should give priority to people with mental disabilities in public and/or subsidized housing schemes.[33] The WHO cites the Finland Mental Health Act which states that, "[i]n addition to adequate treatment and services, a person suffering from a mental illness or some other mental disorder must be provided with a service flat and subsidized accommodation appropriate to the necessary medical or social rehabilitation as separately decreed".[34] Housing legislation can also include provisions to prevent geographical segregation of persons with mental health problems. This may require specific provisions to prevent discrimination in location and allocation of housing for persons with mental health problems.

Housing rights link, of course, to mental health detention. If the law is to allow a person to be detained for a period of time if the mental illness is of a nature or degree warranting detention and that the person poses a serious risk of significant harm, the law must (a) provide actual alternatives (such as care in the community), and (b) contain tightly-drafted exculpatory criteria for compulsion. If these two criteria are not met, then people with mental disabilities will continue to be detained in institutions. As Module 7 points out, the CRPD treaty monitoring body has not yet interpreted detention in the CRPD. There are a range of views as to the circumstances in which, if any, a person with mental disabilities may be detained.

Social security

In addition to housing, a State should also provide social security, according to international human rights laws. States should ensure that people with mental health disabilities can access social security on parity with people who have other sorts of disabilities. Social security systems should not create a disincentive to seek employment – that is they should be flexible enough to allow people to get a paid job without losing the benefits from a disability payment/pension.

Article 9 International Covenant on Economic, Social and Cultural Rights provides the "right of everyone to social security, including social insurance". In its General Comment 5 (1994) on people with disabilities the UN Committee on Economic, Social and Cultural Rights referred to Article 9 of the International Covenant on Civil and Political Rights and emphasized the importance of providing adequate income support to persons with disabilities who, owing to disability or disability-related factors, have temporarily lost, or received a reduction in their income, have been denied employment opportunities or have a permanent disability. Such support, the Committee stated, should be provided in a dignified manner and reflect the special needs for assistance and other expenses often associated with disability. The support provided should cover family members and other informal carers, who are often women.[35] The Committee also said that "[i]nstitutionalization of persons with disabilities, unless rendered necessary for other reasons, cannot be regarded as an adequate substitute for the social security and

[32] Art. 28(2)(d)
[33] WHO Resource Book on Mental Health, Human Rights and Legislation, p. 81.
[34] Mental Health Act, No. 1116, 1990, Finland.
[35] General Comment 5 (1994), para. 28.

income-support rights of such persons".[36] In addressing the right to social security the Committee has more recently stated that governments should pay particular attention people with disabilities as they traditionally face difficulties in exercising this right.[37]

5. Right to vote and stand for election

For the purposes of this section, the right to political life includes the right to vote, and to stand for election. There is much more material on the right to vote, and statistically speaking of course this right is relevant to much larger numbers of people than those who wish to stand for election. The section therefore focuses on the right to vote, from which, in domestic laws of many countries around the world people with mental health disabilities are specifically excluded.

Voting

In general there are four ways in which people with mental health disabilities are excluded from voting.

1. Exclusion because of a diagnosis. For example, the law in Cameroon[38], India[39] and Tanzania[40] exclude people from voting who are of "unsound mind". Thailand excludes anyone "being of unsound mind or mental infirmity" from voting.[41]

2. Exclusion because of location. Some people are denied the right to vote for the entirety of their detention in a psychiatric hospital or other institution. This is the case, for example, in Egypt.[42] There have been recorded instances in other countries of a deliberate attempt by authorities to exclude people in hospital from voting. In Bulgaria in 2003 it was reported that the director of a state psychiatric hospital ordered the psychiatrists working at the hospital to assess the capacity of inpatients to vote, when the director had no power in law to seek to deny the patients their vote.[43]

3. Exclusion because of deprivation or restriction of legal capacity. Hungary's constitution denies adults under guardianship from voting,[44] as does Denmark's.[45] Several other countries have similar provisions not in their constitutions, but in electoral laws, for example Germany.[46]

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[36] General Comment 5 (1994), para. 29.
[37] General Comment 19 (2007), para. 31.
[38] Law on Elections to Parliament and Presidency, Section 15 and Section 6.
[39] 1999: Representation of the People Act, 1950), Section 16(1).
[40] 1995: Elections Act No. 1 of 1985, Article 11.
[41] Constitution (1997) Article 106(1).
[42] July 2000: Law 73 of 1956 on Exercising of Political Rights, Article 3.
[43] See press release by Mental Disability Advocacy Center and Bulgarian Helsinki Committee, 24 June 2005.
[44] Hungarian Constitution, Art. 70(5).
[45] Danish Constitution, Art. 29(1).
[46] Federal Election Law of 1997, Art. 13.

4. Exclusion because of inability to access the polling box. For example, in England and Wales people detained under the mental health law are only allowed to vote by post or by proxy.[47] In other countries polling stations simply do not go to psychiatric hospitals.

You can find out more about discriminatory laws on this website: www.electionaccess.org. For a good practice example, see the South African legislation.[48]

The denial from people with disabilities of a fundamental right of citizenship such as voting likely contributes to the political marginalisation, disenfranchisement and invisibility of people with disabilities in public life and discourse. Their disenfranchisement allows politicians to ignore the views of people with disabilities and dismiss them as second grade people. Modern human rights laws view people with disabilities as holders of human rights, and the CRPD specifically describes people with disabilities "as electors". This vocabulary is part of the paradigm shift towards full recognition and participation in political life.[49]

What does human rights law tell us about people with disabilities and voting? The CRPD establishes a no-exceptions right to vote for people with disabilities. It is clear that any domestic laws which prevent people with any nature or degree of disability from voting – for example people in psychiatric hospitals or people deprived or limited of their legal capacity – will not be in compliance with the CRPD. Furthermore, States need to provide reasonable accommodation in voting. All voting procedures, information and facilities should, according to the CRPD, be accessible to people with disabilities, and that where necessary assistance must be given to people with disabilities to enable them to exercise this right.

Looking at other human rights treaties, the ICCPR provides for the right to vote in Article 25, setting out that everyone has the right and opportunity to vote "without unreasonable restrictions". This has been briefly commented on by the ICCPR's monitoring body which has said that "[a]ny conditions which apply to the exercise of the rights protected by article 25 should be based on objective and reasonable criteria".[50] It does not specify what such criteria could be. In a similar vein, the European Commission for Democracy through Law (the Venice Commission) has said that "[u]niversal suffrage means in principle that all human beings have the right to vote and to stand for election. This right may, however, and indeed should, be subject to certain conditions",[51] and goes on to say that:

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[47] "A person to whom section 7 of the [Representation of the People Act 1983] (mental patients who are not detained offenders) and who is liable, by virtue of any enactment, to be detained in the mental hospital in question; or a person to whom section 7A of that Act (persons remanded in custody) applies … may only vote by post or by proxy (where he is entitled as an elector to vote by post or, as the case may be, by proxy at the election)". (Representation of the People Act 2000, Schedule 4, para 2(6)).

[48] See http://www.electionaccess.org/LR/Countries%20M-Z/South_Africa.htm (last accessed 1 July 2009).

[49] CRPD Art. 29(a)(iii).

[50] General Comment (No. 25(57)) adopted by the Human Rights Committee under Article 40(4) of the ICCPR, 12 July 1996.

[51] Venice Commission, "Code of Good Practice in Electoral Matters", Opinion 190/2002, adopted on 5-6 July 2002 and submitted to the Parliamentary Assembly of the Council of Europe on 6 November 2002.

i. Provision may be made for depriving individuals of their right to vote and to be elected, but only subject to the following cumulative conditions:
ii. It must be provided for by law.
iii. The proportionality principle must be observed; conditions for depriving individuals of the right to stand for election may be less strict than for disenfranchising them.
iv. The deprivation must be based on mental incapacity or a criminal conviction for a serious offence.
v. Furthermore, the withdrawal of political rights or finding of mental incapacity may only be imposed by express decision of a court of law.

The Venice Commission provides neither a definition of "mental capacity" nor guidance as to *why* it treats such people similarly to convicted criminals. Similarly, The Council of Europe's "Principles concerning the legal protection of incapable adults" which provides guidance on guardianship systems, specifies that a measure of protection (such as guardianship) should not *automatically* deprive the person concerned of the right to vote (emphasis added).[52] It does not explain the reasons for, or the circumstances in which the right to vote can be deprived.

These international legal provisions are now little more than historical reference points. As noted above, the CRPD has firmly rejected as unreasoned and unreasonable the proposition that voting rights be removed from people with disabilities.

Country examples

Two examples of how domestic courts have helped push through the right to vote for people with disabilities. In 1976, the Appellate Division of the Superior Court of New Jersey (USA) decided on case of *Carroll v. Cobb*.[53] The court ruled that it was unlawful to deny voting rights of a person merely because that person is receiving care on an inpatient basis in a State facility, or is eligible for such treatment. According to court, the capacity of a person to vote must be based on a court opinion about whether an individual person is able to comprehend the meaning of elections and is able to form an opinion about candidates on a ballot paper.

In 2003 Slovenia's Constitutional Court was asked to rule on the constitutionality of election laws which allowed only people with full legal capacity to register to vote. The court declared that the capacity to vote cannot be equated with general legal capacity and that therefore the election laws were unconstitutional.[54] The court went on to recommend that the law should establish a procedure by which an authority would determine in each specific situation whether a person with intellectual disabilities is capable of understanding the meaning of elections. The Constitutional Court mandated the government and parliament to bring the election laws into conformity with its judgment within six months. This did not happen, so after six months the court's judgment entered into force automatically, and on 29 January 2004 over 3,700 people with intellectual difficulties gained the right to vote.

[52] Recommendation No. R(99)4 adopted by the Committee of Ministers of the Council of Europe on 23 February 1999, Principle 3.
[53] 139 N.J. Super. 439 (App. Div. 1976).
[54] Official Journal of RS, no. 73/29 July 2003, p. 11212-11216.

Standing for election

The CRPD protects the right of people with disabilities "to stand for elections, to effectively hold office and perform all public functions at all levels of government".[55] Similarly to the exclusion from voting, people with mental health disabilities have historically faced absolute exclusion from standing for public office. A recent and public example of a person in high public office who had a mental health disability was the prime minister of Norway, Kjell Magne Bondevik who was elected prime minister in October 1997. In August 1998 he had a depressive illness and immediately came out publicly; at the time he was the highest ranking official worldwide to come out as a person with mental illness. He took three weeks out, and was then re-elected as prime minister in 2001.[56]

One recent example of a country which is trying to change laws which prevent people with mental health disabilities from standing for parliament is the United Kingdom. On 20 July 2008 the UK's Sunday Times reported that the Ministry of Justice is preparing to allow people labelled "idiots" and "lunatics" by archaic laws to stand for parliament.[57] This follows a survey of members of parliament which, reportedly found that 27% had experienced a mental health problem. One in three said the stigma had prevented them from being open about it.

6. Right to marry and found a family

This section deals with the rights of people with disabilities under family law. They include the right to marry, to parent a child, and to retain fertility.

Marriage

People with mental health disabilities have frequently been discriminated against within family law. In many countries people with disabilities deprived or restricted of legal capacity must ask the guardian's permission to marry. Conversely it is sometimes possible for a spouse to place his/her partner under guardianship and then automatically get a divorce.

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[55] CRPD, Art. 29(a)(ii).

[56] More information available on Wikipedia: http://en.wikipedia.org/wiki/Kjell_Magne_Bondevik (last accessed 1 July 2009).

[57] "Lunatics take over Westminster asylum" (Marie Woolfe), The Sunday Times, 20 July 2008. Available online: http://www.timesonline.co.uk/tol/news/politics/article4364377.ece (last accessed 1 July 2009).

Parenting

Matters are more complex when children enter into the picture. The state has an obligation to people to allow them to procreate and raise children. It also has duties towards people under the age of majority to ensure that they are not being abused or neglected, and to ensure that they are nourished, cared for, educated and so on. The exact scope of the state's obligations will vary depending on domestic legislation. The rights of the parent and the rights of the child can of course conflict, and it is in these often difficult cases where the state intervenes for the "best interests" of the child, a foundational concept of child law internationally and a cornerstone of the UN Convention on the Rights of the Child.[58] This Convention states that "[i]n all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration".[59] The CRPD echoes this approach.[60]

Although the UN Convention on the Rights of the Child includes the qualified right of a child to "as far as possible […] to know and be cared for by his or her parents",[61] separating a child from his or her parent(s) is provided for in specific circumstances. Separation is allowed only when competent authorities which make the separation decision can be judicially reviewed, and when it is determined that separation is necessary for the best interests of the child. Note that the word "necessary" is used in the Convention, which is a high standard. The Convention says that separation "may be necessary in a particular case such as one involving abuse or neglect of the child by the parents, or one where the parents are living separately and a decision must be made as to the child's place of residence".[62]
Allegations are sometimes made that parents with mental health disabilities are unable/incapable of looking after their children. There are many cases of children being removed in such scenarios. Some of the myriad problems with overly-intrusive family law mechanisms are unnecessary removal of children from their parents with disabilities; disability specific discrimination (that mental illness may be a reason for removing a child); lack of state funding and/or services to assist the parent to keep the child at home; no or low quality legal advice and representation during legal proceedings; and cursory and low quality evaluations of parenting skills.

It is the last element – evaluation of parenting skills – which is particularly susceptible to critique. Clinicians such as psychologists use an array of methods to assess the mental health and parenting skills. Often psychologists will make a direct recommendation to the judge, and evidence suggests that such opinions are favoured by judges and lawyers,[63] and in many cases such opinions can be decisive. Giving primacy to psychologists has been labelled as ethically inappropriate by some commentators. In a strong critique of the system, Tippins and Wittmann write that psychologists have no valid or reliable methods for determining what is in the best interests of children, yet

[58] The CRC has been ratified by all countries except Somalia and the United States (last checked 1 July 2009).
[59] Article 3(1).
[60] CRPD, Art. 23(2).
[61] UN Convention on the Rights of the Child, Article 7.
[62] UN Convention on the Rights of the Child, Art. 9(1).
[63] Bow, J. N., & Quinnell, F. A. (2004). Critique of child custody evaluations by the legal profession. *Family Court Review*, *42*, 115–126.

often do. “There is no empirically supportable method or principle by which an evaluator can come to a conclusion with respect to best interests entirely by resorting to the knowledge base of the mental health profession”, they conclude.[64] They are critical also towards the lawyers and judges who for their own convenience rely on such evidence, and the commentators recommend that “[a]dvanced education in scientific method and empirical behavioral science research will position lawyers and judges to bring more qualitative analysis to bear upon forensic testimony and produce an essential understanding that the legal system ought not make demands upon behavioral science that it is presently unequipped to meet nor admit recommendations that are not predicated upon an empirically established specialized knowledge base”. [65]

How is mental health relevant to parental rights under international law? Disability – with mental health disabilities included within this term – is firstly relevant in family law because it is one of the protected grounds against discrimination. Article 1 of the UN Convention on the Rights of the Child states that rights within that Convention must be applied without discrimination “of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.” Expanding the non-discrimination provision, the CRPD places an obligation on States “to take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others”.[66]
Building on this, the CRPD places an additional obligation on States to provide “appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities”.[67] This provision may well prove to be useful to parents with disabilities who can argue before a domestic court that they are entitled to a remedy which force the State to provide assistance to them so that they can raise their children. Finally with regard to parenting, the CRPD provides that children must never be removed from parents on the basis of a disability of either the child or one or both of the parents.[68] This may end disability based discrimination, but a sceptic may suggest that States will simply resort to disability-neutral justifications for removing children from parents with disabilities.

Fertility

People with disabilities have historically been denied the possibility of becoming parents, probably because some disabilities can be inherited. Eugenic programmes were set up in various countries because policy-makers believed that sterilizations would prevent the hereditary transfer of mental illness (and intellectual disabilities or “mental retardation” as it was then called) and the undesirable characteristics that accompany these afflictions which cause burdens on society. This view has been debunked by scientists as nonsense, and by human rights people are violations.

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[64] Tippins, T. M., & Wittmann, J. P. (2005) “Empirical and ethical problems with custody recommendations: A call for clinical humility and judicial vigilance” *Family Court Review*, *43*, 193–222 at 215.
[65] Ibid, at 217.
[66] CRPD, Art. 23(1).
[67] CRPD, Art. 23(2).
[68] CRPD, Art. 23(4).

The US was the first country to introduce compulsory sterilization legislation for people with mental health disabilities (and people with intellectual disabilities). Nazi Germany carried on a eugenics programme which of course resulted also in the murder of 200,000 to 250,000 children and adults with disabilities within the "T4 Action".[69] In 1997 it was revealed that Sweden had a compulsory sterilization programme which lasted from 1934 to 1976. According to a year 2000 governmental report, 21,000 people were forcibly sterilized, 6,000 were coerced into a "voluntary" sterilization and 4,000 people were sterilized but the reasons could not be determined. With the backdrop of these governmental policies, the CRPD states simply that "[p]ersons with disabilities, including children, retain their fertility on an equal basis with others".[70]

7. Right to property

The right to property is, expressly mentioned in the Universal Declaration of Human Rights, which states that "[e]veryone has the right to own property alone as well as in association with others",[71] and that "[n]o one shall be arbitrarily deprived of his property".[72] The Convention on the Elimination of All Forms of Discrimination against Women protects the right, the latter protecting against interference to the right of "ownership, acquisition, management, administration, enjoyment and disposition of property".[73] The International Covenant on Civil and Political Rights is curiously silent on the right to property, but the right can be inferred from Articles 1 and 26. The right is also expressed in regional instruments such as the African Charter on Human Rights and Peoples' Rights,[74] and the European Convention on Human Rights.[75] None of these provisions allow any exceptions. On the contrary, all of them prohibit discrimination in exercising rights, including the right to property.

However, the right to property can be is compromised for people with disabilities. Many guardianship laws (see "CRPD's paradigm shift" above) automatically remove the right to property from an adult whose legal capacity has been partially restricted or fully deprived. The decision-making with regard to capacity is handed to the guardian, who may be a relative who wants to dispose of the adult's real estate, for example.

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[69] Wikipedia has comprehensive information on this programme. See http://en.wikipedia.org/wiki/Action_T4 for more information and sources of further information (last accessed 1 July 2009).
[70] CRPD, Art. 23(1)(c).
[71] UDHR, Art. 17(1).
[72] UDHR, Art. 17(2).
[73] CEDAW, Arts. 15 and 16.
[74] See Arts. 13 and 14.
[75] ECHR, Article 1 Protocol 1.

8. Right to education

International law

The right to education is enshrined in the International Covenant on Economic, Social and Cultural Rights, which recognises the right of *everyone* to education, specifying that education "shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms".[76] The IESCR also calls for free primary education, and secondary education which should be available and accessible to everyone".[77]

The Convention on the Rights of the Child came into force in 1989 and expanded on the meaning of the right to education, specifying that education should be directed at the "development of the child's personality, talents and mental and physical abilities to their fullest potential".[78] The Convention on the Rights of the Child additionally states that "a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community",[79] whilst at the same time imposing an obligation on States to ensure that a child with disabilities "has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development".[80]

Regional instruments also provide for the right to education. The Revised European Social Charter being an example. In October 2008 the European Committee for Social Rights decided on the "collective complaint" Mental Disability Advocacy Center v. Bulgaria , and found violations of Articles 17(2) on the right to education and Article E on the non-discrimination) of the Revised European Social Charter. The complaint is taken for several thousand children institutionalised in so-called 'Homes for Mentally Disabled Children'. These institutions are often found in remote areas and staffed by unqualified people with little or no understanding of the needs or rights of children with intellectual disabilities.[81]

Inclusive education

The CRPD, agreed in 2006 (some 17 years after the CRC), covers the right to education also. It goes further than the CRC, in specifying that the right to education means the right to inclusive education, meaning that they are not excluded from mainstream

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[76] ICESCR Art 13(1).
[77] ICESCR, Art 13(2)(b).
[78] CRC, Art. 29.
[79] CRC, Art. 23(1).
[80] CRC, Art. 23(3).
[81] *Mental Disability Advocacy Center (MDAC) v. Bulgaria*. Collective Complaint under the European Social Charter: http://www.mdac.info/en/node/171 (last accessed 1 July 2009).

schooling on the basis of disability.[82] This means that they should receive reasonable accommodation in schools,[83] and be provided with support to help them remain within the general education system.[84] In order for this to happen, the CRPD encourages countries to focus on training teachers in skills which will ensure that children with disabilities receive appropriate education.[85]

So the CRPD states explicitly what had previously only been implied, namely that children with disabilities have the right to inclusive education. The questions remain: what are the features of inclusive education, why is it beneficial, and how can States move towards such a system? In 2007 Vernor Muñoz the UN Special Rapporteur on the Right to Education (an unpaid appointment with a worldwide remit who annually to the UN Human Rights Council) issued a timely report on the right to education for people with disabilities. In his report, the Special Rapporteur observed that "persons with disabilities, of both genders and all ages and in most parts of the world, suffer from a pervasive and disproportionate denial of this right [to education]."[86] Girls and women with disabilities suffer multi discrimination in education evidenced by global literacy rates: for adults with disabilities it is 3%, and 1% for girls and women with disabilities,[87] compared with a world literacy rate of currently 82%.[88]

These staggering differences are due to the denial of education to people with disabilities. In many countries there is a "special education" system. Special education is for children with disabilities and is separate from mainstream schools for children without disabilities. The Special Rapporteur notes that "special schools, often based on the belief that persons with disabilities are uneducable and a burden on the mainstream educational system, often were - and remain - inflexible, non-individual-student specific and they fail to provide or even offer optimum results for their students".[89] He goes on to point out that special schools encourage greater marginalization from society which further entrenches discrimination against people with disabilities, and highlights the inefficiency of maintaining a separate system of education because of the multiple systems of administration, structures and services. Further, research is pointing to the fact that inclusive educational systems are more financially viable. Inclusive education, he says, should be viewed expansively: from early learning, throughout childhood, into adult learning and vocational training. In moving from a special system to an inclusive one, the Special Rapporteur warns against mere *integration*, which he defines as the placing of children with disabilities into mainstream classes without adequate preparation such as reviewing and altering curriculum, structure and teaching and learning styles. Integration without inclusion may lead simply to exclusion in mainstream schools instead of exclusion in special schools.

The Special Rapporteur recommends that governments launch awareness-raising campaigns addressed at parents, teachers and the general community in order to combat discriminatory-held views. Domestic legislation should recognise inclusive

[82] CRPD, Art. 24(2)(a) and (b).
[83] CRPD, Art. 24(2)(c).
[84] CRPD, Art. 24(2)(d).
[85] CRPD, Art. 24(4).
[86] Muñoz 2007, para. 7.
[87] UNESCO, 1998.
[88] UNESCO Global Education Digest 2006 (covering 2000-2004), p. 174.
[89] Muñoz 2007, para. 11.

education as an inherent part of the right to education. States should create minimum standards within the right to education as well as its underlying determinants. They should also create a plan to transition from special education to inclusive education. States should also identify duty bearers, which means those authorities and individuals who have a part to play in the transition, and states should provide resources for the transition to happen. The Ministry of Education should lead the transition, coordinating governmental ministries and agencies (in some countries, special schools are not even designated as such, and are run by a ministry of social affairs). Monitoring the right to education falls is the responsibility of courts, national human rights institutions, ombudsmen, administrative tribunals, government and independent experts and academics. People with disabilities, their relatives and organisations should participate in designing education programmes and curriculum guidelines.

Benefits of inclusion

Such inclusive education as laid out by the Special Rapporteur may seem like a distant dream in some countries. Moving towards such a system will however have beneficial effects beyond the child's right to education being respected. Children growing up with disabled friends in their classrooms will be less stigmatizing as they grow up, and less stigma means more inclusive societies which celebrate diversity, rather than shun it. People with disabilities who have been educated together to those without disabilities will learn how to interact with people which will set them up to participate fully in society. People with disabilities who are educated will become more active in the labour market, a good thing for that individual and his or her family, but also for a country's economy. It is this last aspect, namely the right to work, which this module now turns.

9. Right to work

Where research has been conducted, there is plenty of evidence to suggest that people with mental health disabilities face many sorts of barriers to the right to work. People find it difficult to get employment because employers discriminate against people with mental health disabilities. For example, the majority of European countries where data are available, the employment rates of people with mental health disabilities is between 20 and 30 percent and in the case of people with severe mental health problems like schizophrenia (the majority of whom are 'capable' of working and want to work) employment rates are around ten percent.[90]

According to a WHO report,[91] rates discrimination experienced by people with schizophrenia seeking employment are "high and consistent across countries" of varying income levels.[92] In a cross-sectional survey in 27 countries of 732 people with diagnosed

[90] Kilian R, Becker T. "Macro-economic indicators and labour force participation of people with Schizophrenia" *Journal of Mental Health*. 2007; 16(2): 211-222. Quoted in McDaid (Ed). (2008). Mental Health in Workplace Settings. Consensus paper. Luxembourg: European Communities, p. 9. Available online here: http://ec.europa.eu/health/ph_determinants/life_style/mental/docs/consensus_workplace_en.pdf (last accessed 1 July 2009).

[91] Vulnerable groups in development: the case for targeting mental disability. WHO, Geneva 2009 (forthcoming)

schizophrenia, 70 percent of whom were unemployed, researchers found that 44 percent of respondents experienced discrimination in finding or keeping work.[93]

The WHO goes on to highlight a number of studies which have indicated the reluctance of employers to hire people with mental disabilities.[94],[95] One study in Poland found that 95 percent of employers reported that they would not want to employ a person with schizophrenia for any position.[96] A second study found that 70 percent of respondents believed that people with mental health disabilities should not be employed in certain positions such as providing childcare, working as a physician or any in governmental position.[97] A recent study in Uganda revealed that having a mental health condition was an important reason for why people were not provided with loans for setting up income generating businesses.[98]

People with disabilities are also prone to being accepted only in second rate employment such as sheltered workshops, which offer repetitive work, low pay and bad conditions. Once in employment, employers rarely provide reasonable accommodation to people with mental disabilities. These terms will be explored in this section.

Barriers to employment include the following.[99] The employment of people with disabilities has depended on economic growth which has happened in times of shortage in the labour force. People on unemployment benefits (social security payments/pensions) have little incentive to seek employment because the employment may pay less than the unemployment benefits. Mental health professionals and employers sometimes underestimate the capacities and skills of people with mental health disabilities and overestimate the 'risk' to employers. Employers are reluctant to employ people with a psychiatric diagnosis because of stigma. There has been little research on what sorts of services and interventions are effective in getting people with mental health disabilities into employment and keeping their jobs.

The right to work is found in the International Covenant on Economic, Social and Cultural Rights.[100] Steps taken by governments to achieve this right may include "technical and vocational guidance and training programmes, policies and techniques to achieve steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic

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[92] Thornicroft G et al. Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. *The Lancet*, 2009, 373:408-415.
[93] Thornicroft, G. et al. (2009) "Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey", *The Lancet*, 373:408-415.
[94] Stuart H. Mental illness and employment discrimination. *Current Opinion in Psychiatry*, 2006, 19(5):522-526.
[95] McDaid D. (2008) Countering the stigmatisation and discrimination of people with mental health problems in Europe, European Commission, Luxembourg.
[96] McDaid D. (2008) op cit.
[97] McDaid D. (2008) op cit
[98] Ssebunnya J et al. "Stakeholder perceptions of mental health stigma in Uganda" (2009) *BioMed Central International Health and Human Rights*, 9:5.
[99] These barriers are taken from Boardman, J. (2003) "Work, employment and psychiatric disability", *Advances in Psychiatric Treatment.* 9: 327-334.
[100] ICESCR, Art. 6.

freedoms to the individual".[101] The ICESCR also contains provisions on working conditions and fair pay,[102] and trade union rights.[103]

Several international bodies are of the opinion that the right to work sits centrally within human rights as a conduit to living with dignity and esteem and contributing to society. In its authoritative commentary on the right to work, the ICESCR monitoring body has emphasised that the right to work is "essential for realizing other human rights and forms an inseparable and inherent part of human dignity. Every individual has the right to be able to work, allowing him/her to live in dignity. The right to work contributes at the same time to the survival of the individual and to that of his/her family, and insofar as work is freely chosen or accepted, to his/her development and recognition within the community".[104] An International Labour Organization document similarly states that, "the importance of work and productive employment in any society not only because of the resources which they create for the community, but also because of the income which they bring to workers, the social role which they confer and the feeling of self-esteem which workers derive from them".[105]

Commenting specifically on the right to work of people with disabilities, the ICESCR monitoring body in 1994 explained that the principle of non-discrimination in access to employment by persons with disabilities means that the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts "is not realized where the only real opportunity open to disabled workers is to work in so-called 'sheltered' facilities under substandard conditions".[106] Sheltered employment usually means a low-grade job (eg. in an assembly line), and run by companies which do not employ people in the open market. Their advantage is that they accept people who may otherwise be unable for whatever reason to get a job, but a disadvantage is that employees may find it difficult to move on to other jobs in the open employment market.

In 2005, eleven years after commenting on sheltered employment, the ICESCR monitoring body emphasised that States, "must take measures enabling persons with disabilities to secure and retain appropriate employment and to progress in their occupational field, thus facilitating their integration or reintegration into society".[107] A year later, the CRPD was adopted, which expanded on the right of people with disabilities to work. Article 27 of the CRPD is more comprehensive set of rules than the ICESCR and legislation should contain all of these provisions at a minimum.

An important point to flag is that reasonable accommodation must be provided to people with disabilities in the workplace.[108] The CRPD defines reasonable accommodation as "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

[101] ICESCR, Art. 6(2).
[102] ICESCR, Art. 7.
[103] ICESCR, Art. 8.
[104] Committee on Economic, Social and Cultural Rights, General Comment No. 18 on the right to work (2005).
[105] Preamble to International Labour Organization Convention No. 168, 1988.
[106] ICESCR General Comment No. 5 on persons with disabilities (1994), paras. 20-24.
[107] ICESCR General Comment No. 18 on the right to work (2005), para. 7.
[108] CRPD, Art. 27(1)(i).

human rights and fundamental freedoms".[109] The CRPD specifies that denial of reasonable accommodation constitutes disability based discrimination.

European Union law also protects against discrimination in employment on prohibited grounds including disability. The European Union's Employment Framework Directive implements the principle of equal treatment in employment and training irrespective of disability (and other prohibited grounds) in employment, training and membership and involvement in organisations of workers and employers.[110] It includes provisions on definitions of discrimination and harassment, the prohibition of instruction to discriminate and victimisation, on positive action, rights of legal redress and the sharing of the burden of proof. It also allows for limited exceptions to the principle of equal treatment, for example, where the ethos of a religious organisation needs to be preserved, or where an employer legitimately requires an employee to be from a certain age group to be recruited. Like the CRPD, the Employment Framework Directive requires employers to make reasonable accommodations to enable a person with a disability who is qualified to do the job in question to participate in training or paid labour. Reasonable accommodation in the workplace for people with mental health disabilities could mean, for example, providing mentoring, allowing the person time off to see a doctor or other health or social care practitioners, providing flexible working hours and allowing more breaks.

10. Right to health

Normative framework

As students have already discovered in Modules 3 and 5, Article 13 of the ICESCR provides for "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." The ICESCR's monitoring body emphasised in 2000 the interdependent nature of the right to health by specifying that it "is closely related to and dependent upon the realization of other human rights, as contained in the International Bill of Rights, including the rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement. These and other rights and freedoms address integral components of the right to health".[111]

The Committee emphasises that the right to health is an inclusive right, namely that it "is not confined to the right to health care. On the contrary, […] the right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment".[112] The right to health contains

[109] CRPD Art. 2.
[110] Directive 2000/78/EC.
[111] Committee on Economic, Social and Cultural Rights, General Comment 14 on the right to health, 2000, para. 3.
[112] Ibid, para. 4.

both freedoms (eg. the right to be free from torture, from non-consensual medical treatment and experimentation) and entitlements (eg. the right to a healthcare system which provides services on the basis of equality). The Committee established that there are interrelated and essential elements of the right to health, namely Availability, Accessibility, Acceptability and Quality, known in human rights lingo as "4As and 1Q". We will examine those in relation to people with mental disabilities below.

Special Rapporteur on the right to health

As well as the ICESCR's monitoring body, there is also a UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. The Special Rapporteur reports to the Human Rights Council. In 2005 the (then) Special Rapporteur Paul Hunt focused his annual report (hereinafter "Hunt report") on the right to health for people with mental disabilities.[113] The Hunt report applies the 4As and 1Q to people with mental disabilities as follows:

(a) Availability. There should be sufficient quantity of healthcare facilities and programmes. The precise nature of the facilities, goods and services will vary depending on numerous factors, including the country's developmental level. They will include, however, the underlying determinants of health, such as safe and potable drinking water and adequate sanitation facilities. For some persons with certain psychiatric disabilities, an adequate supply of essential medicines, including essential psychotropic medicines on WHO's List of Essential Medicines, should also be available.

(b) Accessibility. Health facilities, goods and services have to be accessible to everyone without discrimination. Accessibility has four overlapping dimensions:

i. Physical accessibility. Health facilities, goods and services must geographically accessible, for example rural areas must be covered. Facilities must be physically accessible to persons with disabilities (eg. installing ramps, Braille signs etc).

ii. Economic accessibility. Health facilities, goods and services must be affordable for all, including socially disadvantaged groups. Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households.

iii. Information accessibility. Information given about a particular diagnosis or treatment option should be accessible to everyone, such as people from minority languages, and people with intellectual disabilities who may need the information in easy to read format. It should also be available in Braille for people with visual disabilities. Accessibility of information should not impair the right to have personal health data treated with confidentiality.

iv. Non-discrimination. All healthcare goods and services must be accessible to people with mental disabilities, and must not discriminate on the grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation and

[113] Reference number E/CN.4/2005/51, 11 February 2005.

civil, political, social or other status, which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health. States should ensure that persons with disabilities get the same level of medical care within the same system as other members of society, and do not face discrimination on the basis of presumptions of their quality of life and potential.

(c) Acceptability. Health-care facilities, goods and services must be culturally acceptable and respectful of medical ethics. For example, mental health care and support services for indigenous peoples must be respectful of their cultures and traditions. They must be sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned.

(d) Quality. As well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality. This requires skilled medical and other personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation. In the context of mental disabilities this means that, for example, health professionals should be provided with adequate mental health-care training, and adequate sanitary facilities must be assured in psychiatric hospitals and other support services.

The Special Rapporteur suggests that a further framework to analyse the right to health is the trio of obligations to "respect, protect and fulfill": [114]

1. The obligation to **respect** requires States to refrain from denying or limiting equal access to health-care services, as well as to underlying determinants of health, for persons with mental disabilities.

2. The obligation to **protect** means that States should take actions to ensure that third parties do not harm the right to health of persons with mental disabilities. This might include protections against violence against women with mental health problems.

3. The obligation to **fulfil** requires States to recognize the right to health in national political and legal systems, with a view to ensuring its implementation. States should adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards this end. Paul Hunt gives examples of how this might happen. Hunt says that States should ensure that the population's right to the highest attainable standard of mental health, and the right to health of persons with mental disabilities, are adequately reflected in national health strategy and plan of action, as well as other relevant policies, such as national poverty reduction strategies, and the national budget. It is important that States adopt mental health laws, policies, programmes and projects that:

embody human rights and empower people with mental disabilities to make choices about their lives;
give legal protections relating to the establishment of (and access to) quality mental health facilities, as well as care and support services;
establish robust procedural mechanisms for the protection of those with mental disabilities; ensure the integration of persons with mental disabilities into the community;

[114] Hunt report, paras. 47-50.

and promote mental health throughout society.

CRPD

The discrimination faced by people with mental disabilities within the healthcare system is addressed by the CRPD in its Article 25, in which people with disabilities must be given "the same range, quality and standard of free or affordable health care and programmes as provided to other persons".[115] It should be mentioned that sexual and reproductive health is specifically highlighted as being within the range of health care and programmes to which people with disabilities have equal access. The CRPD also says that health services as close as possible to people's own communities, including in rural areas.[116]

Of particular note is paragraph (d) of Article 25 which provides for medical treatment to be provided "on the basis of free and informed consent". The Convention gives no further guidance as to what this means. Does it mean, for example, that unless there is no consent, no treatment can be given? This would cause problems for example for people who lack capacity to give consent – such as the classic (and extreme) example of someone in a coma, someone who has just been knocked down by a car and is unconscious, or (less extreme example) someone with profound intellectual disabilities who has cognitive and communications difficulties and high dependency needs. Some organisations, including for example the "World Network on Users, Ex-Users and Survivors of Psychiatry", are encouraging an interpretation which makes unlawful all forms of forced intervention.[117] How will the CRPD deal with people who cannot at the relevant time provide consent? How does Article 25 link with Article 12 on supported decision-making? We must wait until the treaty monitoring body is established for an authoritative interpretation of the Convention.

Also of note is that the Article includes health-related rehabilitation, linking with Article 26 on habilitation and rehabilitation which provides for health-related re/habilitation to "enable persons 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".[118] Such initiatives should begin at the earliest possible stage, be based on a multidisciplinary assessment of individual needs and strengths,[119] be voluntary, and be available as close as possible to the individual's community,[120] and be provided by trained staff.[121]

The right to health is also protected in the International Convention on the Elimination of Discrimination Against Women,[122] International Convention on the Elimination of All

[115] CRPD, Art. 25(a).
[116] CRPD, Art. 25(c).
[117] Position paper on the CRPD, issued by the World Network on Users, Ex-Users and Survivors of Psychiatry, 2008.
[118] Art. 26(1)
[119] Art. 26(a).
[120] Art. 26(b).
[121] Art. 26(2).
[122] Arts. 12 and 14 (2)(b).

Forms of Racial Discrimination[123] and the Convention on the Rights of the Child.[124] In regional human rights treaties it is provided for in the American Convention on Human Rights: Additional Protocol,[125] European Social Charter[126] and the African Charter on Human and Peoples' Rights.[127]

Case examples

The African Commission on Peoples' and Human Rights dealt with a case on the right to health (and other rights) of people with mental disabilities in the case of *Purohit and Moore v. The Gambia*.[128] The complainants in this case were mental health advocates from the UK visiting the Gambia, and submitted the communication on behalf of patients detained at Campama, a Psychiatric Unit of the Royal Victoria Hospital, and existing and 'future' mental health patients detained under the mental health laws (including one called the Lunatic Detention Act: how's that for stigmatising?!) of the Republic of The Gambia. The Complainants alleged that the Lunatics Detention Act failed to define 'lunatic', and that there are no provisions and requirements establishing safeguards during the diagnosis, certification and detention of such people. The complainants also alleged that there was overcrowding in the psychiatric unit, and there no requirement for the hospital to gain consent by the patients to treatment, nor was there any review of the treatment, nor any independent examination or review of anything within the unit itself.

In ruling on the case, the African Commission on Peoples' and Human Rights held that the "[e]njoyment of the human right to health as it is widely known is vital to all aspects of a person's life and well-being, and is crucial to the realisation of all the other fundamental human rights and freedoms. This right includes the right to health facilities, access to goods and services to be guaranteed to all without discrimination of any kind".[129] The Commission went on to say that people with mental health problems "should be accorded special treatment which would enable them not only attain but also sustain their optimum level of independence and performance in keeping with Article 18(4) of the African Charter and the standards applicable to the treatment of mentally ill persons as defined in the Principles for the Protection of Persons with Mental Illness and Improvement of Mental Health Care." (para. 81).

The Commission found that the Lunatic Detention Act lacks any therapeutic objectives and lacks any provision of matching resources and programmes of treatment of persons with mental disabilities, a situation which breaches the requirements laid down in Articles 16 and 18(4) of the African Charter. The Commission found The Gambia in violation of Articles 16 and 18(4) of the African Charter, and in doing so stated that,

millions of people in Africa are not enjoying the right to health maximally because African countries are generally faced with the problem of poverty which renders them incapable to provide the necessary amenities, infrastructure and resources that facilitate the full

[123] Art. 5.
[124] Art. 24
[125] San Salvador Protocol, Arts. 10 and 11.
[126] Art. 11.
[127] Art. 16.
[128] Communication No. 241/2001, Sixteenth Annual Report 2002/2003, Annex VII.
[129] *Moore v. The Gambia*, op cit, para. 80.

enjoyment of this right. Therefore, having due regard to this depressing but real state of affairs, the African Commission would like to read into Article 16 the obligation on part of States party to the African Charter to take concrete and targeted steps, while taking full advantage of its available resources, to ensure that the right to health is fully realised in all its aspects without discrimination of any kind.[130]

Lastly, one example of a country-wide investigation into inequalities faced by people with disabilities in the healthcare system. In 2006 the United Kingdom's Disability Rights Commission (which is now part of the Equality and Human Rights Commission) carried out extensive research and produced a report about these issues.[131] It found that people with mental health disabilities people are much more likely than other citizens to have significant health risks and major health problems. For people with mental health problems this includes obesity, smoking, heart disease, high blood pressure, respiratory disease, diabetes and stroke. The investigation also found that people with schizophrenia are almost twice as likely to have bowel cancer as other citizens. The investigation suggested several reasons for inequalities, including social deprivation, but emphasised that the differences cannot be explained by social deprivation alone. The investigation highlighted 'diagnostic overshadowing', that is reports of physical ill health being viewed as part of the mental health problem and therefore not investigated or treated.

11. Right to participation and association

The last section in this module on being included in the community addresses issues around participation in policy and law reform, and around freedom of association. These topics are important because the experience of many people with disabilities is that non-disabled people decide *for* them, from laws and policies down to the everyday issues such as food and clothes. If societies are to change, then governments and other authorities need to change the way that they include people with disabilities in formulating, drafting, implementing, monitoring and evaluating laws, policies and services.

It is important that countries and local authorities support the creation of, and encourage the participation in public policy-making, of service user organisations. Such organisations can play varied roles, such as:

- Running lay advocacy services in community settings and in mental health and social care institutions and. Lay advocates can inform people with disabilities of their rights, help them negotiate the system by facilitating meetings with nurses, or helping the person with making a complaint, for example.
- Such organisations can also run services such as self-help groups for other people experiencing mental health problems.

[130] *Moore v. The Gambia*, op cit, para. 84.

[131] Disability Rights Commission, 2006, "Equal Treatment: Closing the Gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems". Available online at http://83.137.212.42/sitearchive/DRC/library/health_investigation.html (last accessed 1 July 2009).

- User organisations can play a crucial advocacy role. It is only when policy-makers know the needs and desires of people with disabilities that they can do something about it.

Given the advantages to people with mental disabilities and to societies at large of encouraging the formation of associations, it may come as a surprise that freedom of association is sometimes denied for people with mental health disabilities. For example, people deprived of legal capacity in many countries are denied the right to form and join associations.[132] Article 22 of the ICCPR provides for the freedom of association for everyone. The CRPD deals with the right to association in more detail. It obliges States to create a society where people with disabilities can "effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs".[133] Specifically, States are expected to encourage the participation by people with mental health disabilities in non-governmental organisations and associations in general,[134] and such organisations and associations which represent people with disabilities at international, national, regional and local levels.[135] The CRPD explicitly provides for such organisations to be involved and participate fully in the CRPD national monitoring process.[136]

Legislation should encompass all of these aspects and governmental policies and programmes should actively encourage people with disabilities to form and join organisations so as to participate in public life. This encouragement may include providing funding and other support to membership organisations to allow them to function effectively.

[132] See for example, Guardianship and Human Rights in Bulgaria, op cit, p. 50.
[133] CRPD, Art. 29(b).
[134] CRPD, Art. 29(b)(i).
[135] CRPD, Art. 29(b)(ii).
[136] CRPD, Art. 33(3).

3. Core reading

UN instruments [not provided in the module reading]

Convention on the Rights of Persons with Disabilities, Adopted by UN General Assembly on 13 December 2006.

International Covenant on Civil and Political Rights (1966). Adopted by UN General Assembly Resolution 2200A (XXI) of 16 December 1966. (see also General Comments of the Human Rights Committee)

International Covenant on Economic, Social and Cultural Rights (1966). Adopted by UN General Assembly Resolution 2200A (XXI) of 16 December 1966 (see also General Comments of the Committee on Economic, Social and Cultural Rights)

Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993). UN General Assembly Resolution 48/96 of 20 December 1993

Books / articles / reports

Accordino, M. P., Porter, D. F. and Morse, T. (2001) "Deinstitutionalization of Persons with Severe Mental Illness: Context and Consequences", *Journal of Rehabilitation*, April-June

Council of Europe, Committee of Ministers Recommendation No. Rec(99)4 on principles concerning the legal protection of incapable adults, 23 February 1999

Goffman E. (1961) *Asylums. Essays on the social situation of mental patients and other inmates*, Harmondsworth: Penguin, 1968. First published New York: Doubleday Anchor, 1961 [not provided in the module reading]

Gordon, R. M. (2000) "The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making" 23(1), *International Journal of Law and Psychiatry*, January-February, pp. 61-77.

Paul Hunt, Report to the Human Rights Commission by the UN Special Rapporteur on the Right to Health, ref. E/CN.4/2005/51, 11 February 2005

Karlawish, J. H. and Bonnie, R. J., "Voting by Elderly Persons with Cognitive Impairment: Lessons from Other Democratic Nations" (2007) 38 *McGeorge L. Rev.* 879

Mental Disability Advocacy Center (2007) "Guardianship and Human Rights in Bulgaria".

Muñoz, V., "Report of the Special Rapporteur on the right to education: The right to education of persons with disabilities", A/HRC/4/29, 19 February 2007

Parker, C. and Clements, L. (2008) "The UN Convention on the Rights of Persons with Disabilities: a New Right to Independent Living?" E.H.R.L.R., issue 4

The Sunday Times (Marie Woolfe) “Lunatics take over Westminster asylum”, 20 July 2008

WHO Resource Book on Mental Health, Human Rights and Legislation. (2005) World Health Organisation, Geneva [not provided in the reading]

Cases

Purohit and Moore v. The Gambia, African Commission on Human and Peoples’ Rights, Communication No. 241/2001

Shtukaturov v. Russia, European Court of Human Rights, Application No. 44009/05, judgment 27 March 2008