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GLOBAL HEALTH: NON COMMUNICABLE DISEASES (ONLINE DISTANCE LEARNING)

→ WEEK 4

MSc, PgCert, PgDip, PgProfDev

UNIVERSITY OF EDINBURGH

Global Health: Non Communicable Diseases
(Online Distance Learning)

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Global Burden of Mental Illness, Week 4:
Mental Health, Law and Human Rights

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Learning Objectives: Understanding mental disorders

- **1.** Appreciate the role of legislation in the management of mental disorders and key components of mental health act legislation and interface with criminal law
- **2.** Understand the role of the law in protecting the rights of persons suffering from a mental disorder: national and international legislation
- **3.** Have an awareness of the Human Rights abuses that may be experienced by persons experiencing a mental disorder
- **4.** Understand the role of advocacy
- **5.** Consider Public Health interventions that could protect human rights and improve treatment of persons with a mental illness or learning disability from a human rights perspective.

Introduction

In delivering the above objectives this session will provide an overview of two main aspects of law as it pertains to mental disability; namely, law as it applies to policy makers and law as it engages persons with mental disability.

In this context "mental disability" is a broad category used to refer not only to those with mental illness but also those with intellectual disability. This broad coverage does not suggest that intellectual disability and mental illness are clinically the same; the mental difficulties, lives, care and treatment of persons affected by these issues are very different. Rather, people with intellectual disability and people with mental illness suffer from similar barriers, prejudices, negative attitudes, abuse and discrimination in society, which has a significant impact on law's relevance to such persons.

Please note that human rights and mental disability can raise some challenging personal and professional issues. Moreover, studying law can be exciting and challenging in using new concepts but can also require considerable reading. We strongly recommend that you start by reading the *essential* course materials and engage in the *essential* exercises. Optional reading and exercises have been provided to allow you to pursue your interests and develop your understanding further should you find time.

Session structure

This session is framed around the following lecture, reading and exercises:

<u>Reading</u> is marked in red. Key reading has been marked in bold and designated with an asterix (e.g. * Key reading). Reading that may further develop your understanding but is not compulsory is not marked in bold (e.g. further resources).

<u>Exercises</u> are marked in blue. Essential exercises in which you *must* post a contribution are marked in light blue and bold (e.g. **Key exercise**). Optional exercises that you might like to post a contribution on or consider on your own are marked in green and bold (e.g. **Optional exercise**). You may find it helpful to consider these exercises whilst reading the key reading.

The individual assignment for the week is marked in dark blue and bold (e.g. Individual assignment).

Component 1: Mental disability and the law

4.1.1 What is law?

Law generally serves to regulate relations between autonomous entities to achieve a given range of policy objectives, usually in the name of public interest. In doing so, law is both a shaper of society and a product of it.

The law's emphasis on autonomy and responsibility means that mental disability can present difficult and complex issues for how it interacts with persons with mental disability. Here, just law must balance not only the interests of the public with the interests of those with mental disabilities, but also an individual's interest in maintaining their freedom with their need for protection where they are rendered vulnerable by mental disorder. This raises fundamental questions about "personal autonomy and liberty, the role of the state and the extent of its powers and responsibilities, public attitudes towards people who are mentally-ill, developments in medical and behavioural sciences, the clinical judgment of medical practitioners and other professionals and complex questions of medical science, ethics and belief." (UK Joint Committee on the Draft Mental Health Bill, First Report, para.8). The state's response to these difficult issues often falls under the rubric of mental health law.

In most countries law has come to regulate how power itself can be exercised, not only regarding the application of law but also how law itself is formulated. Laws can stipulate the things that someone in power should not do (negative law), e.g. detain people without a fair reason or refuse to recognise their decisions as valid and equal in law. It can also outline things that an authority should do (positive law), e.g. protect those who are vulnerable in society. Being concerned with the legitimacy of state action such law is often found in constitutional documents. Its clearest example lies in human rights law.

This module is primarily concerned with mental health law and international human rights law. It will outline key features of the former whilst explaining how the latter provides a framework for the formulation of mental health law and policy.

4.1.2 Stigma, stereotyping, discrimination and human rights

Society's inability to understand those with mental disability has lead public perception to foster damaging stereotypes and stigmatise those living with mental disabilities. Stereotypes include perceptions of those with mental health problems as dangerous, destitute and lacking in mental ability. They can also foster views of persons with mental disability as being socially and economically unproductive and often fail to recognise a person's ability to recover from mental illness.

As law often reflects public perception, these harmful stereotypes can also penetrate law. Here, law's silence on the lives on persons with mental disability can be as harmful as explicitly discriminatory rules. It can maintain or even sanction damaging cultures and practices, resulting in the provision of inappropriate treatment and care; stripping individuals of their rights, rendering them even more vulnerable to abuse; and, at worst, facilitating a refusal to recognise the dignity and humanity of persons with mental disability. As such, law's role in facilitating and perpetrating harm against persons with mental disability is as real as its capacity to offer them crucial protections.

The significant discrimination and misunderstanding faced by persons with mental disability can make them the most disenfranchised and vulnerable members in society, rendering them subject to some of the worst human rights abuses. This fact (and, until recently, its apparent acceptance) has led some states to abuse psychiatric interventions to deal with persons deemed to be "undesirable".

*'Human Rights Abuses in Mental Institutions Common Worldwide, Perlin Says', 2006, http://www.law.virginia.edu/html/news/2006.sp r/perlin.htm

Bartlett, P., and Sandland, P., Mental Health Law: Policy and Practice, (2003: OUP), Chapter 1, pages 1-10:

http://www.oup.com/uk/orc/bin/9780199278275/bartlett&sandland ch01.pdf

Human rights are founded upon the recognition of the inherent humanity and dignity of all persons. Core human rights can be found in the international bill of rights (composed of the UN Declaration of Human Rights, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR)). These rights include civil and political rights (ICCPR), such as the right to life (Article 6), the right to freedom from torture and cruel, inhumane and degrading treatment (Article 7), the right to liberty and security of person (Article 9) and the right to respect for humanity and inherent dignity where liberty is deprived (Article 10). They also include economic, social and cultural rights (ICESCR), such as the right to an adequate standard of living (Article 11), the right to the highest attainable standard of physical and mental health (Article 12) and the right to education (Article 13). In providing these rights all three documents emphasise that they should be respected and ensured "without distinction of any kind" (common Article 2, ICCPR/ICESCR), which means that discrimination, including on grounds of disability, is prohibited under human rights law.

China's mental health law: A landmark mental health bill is currently passing through the Chinese legislature. The proposed law highlights the rights of patients regarding psychiatric hospital admission, treatment, privacy and discharge, as well as recourse where rights are believed to have been violated. To date, China has had no legislative guidance on compulsory psychiatric admission and discharge. As such, "the current daily practice in China is that individuals who are suspected of having mental disorders are often compulsorily admitted to psychiatric hospitals with the consent form signed only by family members. Usually only the person who signed the consent form for the admission is then allowed to apply for the patient's discharge." (Xiang, Yu et al, 'China's National Mental Health Law: 379 26-year work in progress' 2012, The Lancet 780, available http://www.lancet.com/journals/lancet/article/PIIS0140-6736(11)61704-2/fulltext; 'Psychiatric institutions in China', 2010, 376 The Lancet 2, available at: http://www.lancet.com/journals/lancet/article/PIIS0140-6736(10)61039-2/fulltext#)

Chinese law forbids the marriage of persons with certain acute mental illnesses, such as schizophrenia. If doctors find that a couple is at risk of transmitting disabling congenital defects to their children, the couple may marry only if they agree to use birth control or undergo sterilization. The law stipulates that local governments must employ such practices to raise the percentage of healthy births. (US Department of State, Country Reports on Human Rights Practices 2011, China, available at: http://www.state.gov/j/drl/rls/hrrpt/humanrightsreport/index.htm?dlid=186268). In 2005, media reports publicized the forced sterilization of teenagers with mental disability in Nantong, Jiangsu Province.

Total and partial failures to recognise the humanity of persons with mental disability occur not only in their communities but also in so-called care settings:

"Poor quality services and human rights violations in mental health and social care facilities are still an everyday occurrence in many places, especially in low- and middle-income countries... Decrepit buildings, overcrowding and unhygienic living conditions are a reality for many people living in psychiatric institutions. In many facilities, people are exposed to violence, abuse, harmful treatment and neglect. Many are locked up against their will, overmedicated, put in seclusion cells or restrained, sometimes for years." Dr Shekhar Saxena, Director of WHO's Department of Mental Health and Substance Abuse.

* 'Mental Health and Human Rights: Denied citizens' WHO, available at:

http://www.who.int/features/galleries/2005/mental health/01 en.html



Watch this clip of Gabor Gambos, a Hungarian psychiatric survivor and human rights activist who has campaigned to eradicate the use of caged beds in Hungarian psychiatric institutions: http://www.youtube.com/watch?v=xrhwt-JmqLw.

Please also watch one more of the short videos below. These videos provide examples of the types of human rights violations to which persons with mental disability can be subject. Please note that the conditions depicted in some of this footage may be distressing for those not used to such conditions.

- 'Behind closed doors' 2007. An investigation on the human rights of persons with mental disabilities in Turkey, by Lazarina Todorova and Mental Disability Rights International, available at: http://www.youtube.com/watch?v=Q9INUsLLC8c. Note that Turkey has now prohibited the use of electroshock treatment without anaesthesia.
 - 'Mental health', 2011, Reportage on Kenyan mental healthcare provision by Cathy Majtenyi of Voice of America on In Focus, available at: http://www.youtube.com/watch?v=IT3bfymB_7I.

Post your thoughts on the relationship between mental health care providers/public health interventions and law in ensuring that persons with mental disability enjoy their basic rights? In doing so, try to give examples from both of the videos you watched. Respond to the posts of others.

4.1.3 Mental health law and the management of mental disorder

Due to the centrality of mental capacity to our many interactions, law concerning mental health can be found in most legal sectors including housing and homelessness law, criminal law, social security law, family law and the law of contract. All these areas of law may either make some reference to mental state to which mental disability might pertain, may make specific provision for mental disability, or both. Moreover, law relevant to protecting the rights of mentally disabled persons can also be found in legislation that is not specific to mental health such as constitutional law, employment law and equality and discrimination law.

In the delivery of public health, mental health law is an important means of re-enforcing the goals and objectives of mental health policy by providing a legal framework for its implementation, enforcement and development. As such, having specific mental health law provides a means of focusing efforts and

resources to improve mental health. For example, it can create oversight mechanisms and allocate necessary resources to the mental health sector; bestow rights and entitlements on mental health consumers that are enforceable through judicial or quasi judicial organs; and impose broad and specific duties on those engaging with mentally disabled persons which necessitate the review and reformulation of policies and practices in line with those obligations (e.g. non-discrimination, confidentiality, promotion of community integration). In this way, mental health legislation can act as an impetus for progressive cultural change in mental health practice.

Mental health legislation in the world: The WHO's Mental Health Atlas 2011 found that only 59% of people worldwide live in a country where there is dedicated mental health legislation. This statistic was affected by countries like China which still lacks dedicated mental health legislation. Among countries with dedicated mental health legislation, 42% were enacted or revised in 2005 or later, while 15% still used legislation enacted before 1970. Moreover, these states represented 77% of high income countries in comparison with only 39% of low income countries.

Notably, the study also found that 60% of countries reported having a dedicated mental health policy and 71% possessing a mental health plan.

See Mental Health Atlas 2011, WHO:

http://whqlibdoc.who.int/publications/2011/9799241564359 eng.pdf

As mental health legislation and policy go hand in hand, policy objectives determine how law regulates the lives of mentally disordered persons. Before the 1970's mental health law often reflected certain stereotypes of mental disorder, often leading to laws and practices that could violate the rights of individuals with mental disability. Growing awareness means that it is now generally recognised that the basic function of mental health legislation is to protect, promote and improve the lives and mental well being of a State's citizens.

*Read pages XV and 1-7 of the WHO Resource Book on Mental Health, Human Rights and Legislation, available at:

http://www.who.int/mental health/policy/who rb mnh hr leg FINAL 11 07 05.pdf

For more read pages 2-7 and 9-12 of *Mental Health Legislation and Human Rights*, WHO Mental Health Policy and Service Guidance Package, 2003, available at: http://www.who.int/mental health/resources/en/Legislation.pdf

In defining the scope of legal powers and entitlements under mental health law, legislation generally defines the persons to whom such powers and entitlements should apply. Such definitions are extremely important to ensuring that legislation is not over or under inclusive. Indeed, a legal finding of mental disorder carves a profound dividing line between those held responsible for their actions and able to make decisions, and those potentially subject to confinement against their will, loss of control over their property and affairs and involuntary treatment sometimes with potentially serious consequences. Likewise, it is crucial that those who need to access health services, are vulnerable to abuse or are unable to manage their day to day lives are not excluded from the protection of the law. It is therefore essential that the criteria used to define such persons is appropriate to the true function that legislation is intended to serve generally and in the context of specific provisions.

* WHO's Resource book on Mental Health, Human Rights and Legislation, pages 20-27(section 3 of Chapter 2), 2005, available at: http://www.who.int/mental-health/policy/who-rb-mnh-hr-leg-FINAL-11-07-05.pdf

Defining mental disorder in the UK: Prior to 2008, s.1(2) of the UK's Mental Health Act 1983 defined its application by reference to the defined terms of 'mental disorder', 'severe mental impairment', 'mental impairment' and 'psychopathic disorder', with each term acting as a gateway definition for a variety of different mental health interventions. The Mental Health Act 2007 simplified the definition of the conditions to which the Mental Health Act applies to simply "mental disorder", defined as "any disorder or disability of the mind". This simplified definition, which generally excludes those with learning disabilities and those dependant on drugs and alcohol, acts as a diagnostic criteria for all sections of the Act.

By contrast Scotland's Mental Health (Care and Treatment) (Scotland) Act 2003 defines mental disorder to mean any mental illness, personality disorder or intellectual disability, and lists factors that cannot alone be taken to mean that a person has a mental disorder. These factors include sexual orientation, sexual deviancy; transsexualism; transvestism; dependence on, or use of, alcohol or drugs; behaviour that causes, or is likely to cause, harassment, alarm or distress to any other person; and acting as no prudent person would act.

Optional Exercise A: What are the possible advantages and disadvantages of these approaches? To what kinds of public mental health provision or intervention might other terms such as mental illness, mental disability and mental incapacity be helpful?

Mental Health Alliance House of Commons Committee stage amendment briefing on exclusions to the definition of mental disorder:

http://www.mentalhealthalliance.org.uk/policy/documents/Commons Cttee Stage Definition Exclusions.pdf

The coverage of mental health law can vary from country to country; in a number of states such law might merely address involuntary admission and treatment, whereas in others it can govern the type of care and treatment a person should receive, when and how a guardian should be established, how people should be treated in care facilities, etc.

The WHO recommend provision be made in mental health law for the following:

1. Access to mental health care. This might include provisions relating to the allocation of resources and funding to the mental health sector through provisions requiring equity with the physical health sector, specifying new service requirements necessitating additional funding, or establishing mental health review boards/tribunals. It can also include the introduction of mental health service

- provision in primary care settings, the establishment of criteria for needs-based assessments and the inclusion of mental health care under insurance coverage.
- 2. The rights of mental health service users and their families, including the fundamental right to confidentiality, access to information, privacy communication with the outside world, freedom from forced labour, information on rights, participation rights (in the formulation of treatment plans, legal proceedings and mental health policies and planning).
- 3. Definitions, assessment procedures and provision for incompetence and incapacity, including for example guardianship.
- 4. The criteria and procedures to be followed for voluntary and non-voluntary admission and treatment, including provisions relating to review, conditions of discharge, proxy consent to treatment, community based involuntary care and emergency situations.
- 5. **Professional standards and accreditation** for staff members determining mental disorders.
- 6. Definitions of, procedures for, and strict restrictions on, the use of seclusion and restraint, as well as the promotion of infra-structure and resource development to reduce the need for such measures.
- 7. Provisions regulating the use of special treatments and clinical and experimental research in lie with medical ethical standards.
- 8. Oversight and review mechanisms to protect the rights of those with mental disorders.
- 9. **Justice sector interactions** with persons with mental disorder, including police responses to persons with mental disability and the handling of mentally ill offenders.
- 10. **Offences and penalties aimed at protecting persons** with mental disorder from exploitation and abuse.
- 11. **Protections for particularly vulnerable groups** such as women, children, minorities and refugees.

*Read pages 21-30 of Mental Health Legislation and Human Rights, 2003, WHO: http://www.who.int/mental_health/resources/en/Legislation.pdf.

For more detail see WHO Resource Book on Mental Health, Human Rights and Legislation, 2005, pages 27-89: http://www.who.int/mental health/policy/who rb mnh hr leg FINAL 11 07 05.pdf

Mental health law in focus: Involuntary admission to hospital – balancing autonomy and protection

As outlined at the beginning of this lecture, the protection of autonomy is a central theme of law. The freedom to make one's own decisions holds compelling moral force that is often closely tied to notions of justice; interference with it therefore requires clear justification. In the mental health context this justification is often founded on the public interest in preventing harm or paternalism in seeking to improve the situation of persons with mental disability. In overriding a person's decision to refuse treatment international guidelines have sought to ensure that the balance between the necessity of overriding such a decision and maintaining the individual's right to self determination. In many states a combination of some of the following legal mechanisms are used:

<u>Diagnostic thresholds:</u> These define the mental disorders to which provisions allowing interference with liberty are applicable (See box X). They can often reflect whether such provisions are predominantly concerned with treatment or protection of the public.

<u>Therapeutic aim requirement</u>: Here, detention can only be justified where there is a therapeutic aim. Thus it is not justifiable for people with conditions that are not treatable, such as intellectual disability. This approach is predominant in European jurisdictions.

<u>Risk test</u>: Here, restriction of liberty is only justifiable where it seeks to prevent harm either to the individual or the

public. The use and stringency of this test can be strongly influenced by public values and perceptions of mental disorder.

<u>Capacity test</u>: This test recognises that some mental disorders affect a person's decision making capacity leading them to refuse treatment that could prevent negative outcomes such as destitution. Again, the use and stringency of this test can be influenced by public perspectives and it can come into play in a number of mental health interventions.

<u>Independent reviews</u>: These are recommended by international guidelines in preference to appeals because they do not require to be triggered by the patient. They are intended to ensure that intervention is only undertaken as long as the individual meets the diagnostic criteria. However, such reviews can have resource implications that must be considered.

* Fistein, E.C., Holland, A.J., Clare, I.C.H., and Gunn, M.J., 'A comparison of mental health legislation from diverse Commonwealth jurisdictions', In J Law Psychiatry, 2009 (May) 23(3) pages 147 to 155. Please read only sections 1, the first 2 paragraphs of section 2 and section 4 (you may exclude the recommendations): http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2687511/

Optional Exercise B: What are your thoughts on overriding a person's consent for the purposes of treatment? For example, do you think it is always justified? Where would you set the boundaries? What kind of safeguards would you use?

4.1.5 Criminal law and mental disability

Our ability to comply with law relies on our ability to understand the proper context in which our actions take place and to have some idea of the consequences of those actions. It also requires a certain degree of control over one's behaviour so that we have a choice as to whether or not we will act in conformity with our understandings. These prerequisites broadly form the basis for legal responsibility for ones actions. The issue of mental disorder raises questions about the just limits of criminal law and its social function as a deterrent and a gateway to rehabilitation. Most jurisdictions at some level recognise the principle that those suffering from mental disorder are not fit and proper subjects of traditional criminal justice. This is because either they cannot be deemed morally blameworthy due to their inability to exert true volition over or understanding of their crimes, and/or the impotence of punishment on such persons.

In this regard, criminal law often makes explicit provision for mental disorder in two circumstances:

- (1) Where someone was suffering from a mental disorder at the time of committing an offence and should not therefore be treated the same as an ordinary criminal. Here a finding of mental disorder will usually result in a "not guilty by reason of mental disorder/insanity" verdict and can trigger diversion into the mental health care system.
- (2) Where someone is suffering from a disorder that means that it is not possible for them to take a meaningful part in their trial. This could impinge on the right to a fair trial. Here a finding of mental disorder will usually trigger diversion into the mental health system until such time as the individual is fit to be tried.

The tests for determining these two mental states are usually considerably different. The former often refers to an accused's knowledge or capacity to understand his acts, his ability to control his behaviour, or both. By contrast, determining mental state for the purposes of fitness to stand trial predominantly

focuses on the accused person's capacity to understand the nature and object of the proceedings being brought against him, the possible consequences of the proceedings and to communicate effectively with their legal representative.

Both these tests usually embody a tension between legal and psychiatric understandings of mental disorder. For example, in seeking to determine the issue of legal responsibility the former test uses legal criteria the factual establishment of which requires medical evidence. Thus for example, the much used McNaughten rules determine the scope of the "insanity" defence as requiring that an accused person either did not know the nature or quality of the act that they were committing, or, if they did, that they did not know that what they were doing was wrong. In maintaining a narrow focus predicated on attributing legal responsibility rather than addressing the impact of mental disorder on the defendant these rules have been criticised for failing to keep those with clear mental disabilities out of the criminal justice system. Nevertheless, some commentators have also criticised approaches predicated on psychiatric definitions of disorder as removing decisions about legal responsibility from the judicial system and placing them in the hands of medical personnel. Such fears have been stoked by theories such as those of Henry Maudsley, which tended towards the view that all criminal behaviour was a function of mental disorder.

For further analysis of the limits for criminal liability for persons with mental disability see Tadros, V., 'Insanity and the Capacity for Criminal Responsibility', 2001 Vol.5 Edinburgh Law Review 325-354, available through Heinonline via Edinburgh E-Journal catalogue.

The issue of mentally disordered offenders is one that is often highly politicised, with lawmakers and lawyers seeking to balance an accused's rights with the need for justice to be seen to be done. In some cases, the public need for accountability, particularly for serious crime, can lead to the perception that

Discerning criminality from mental disorder in Norway: On 24 August 2012 Anders Breivik was found to be sane and convicted for the murder of 77 people and the injury of 242 people on 22 July 2011 in the worst terrorist attack Norway has ever seen.

Måseide, H., 'The Battle about Breivik's mind', The Lancet, 30 June 2012: http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)61048-4/fulltext and 'Anders Behring Breivik: Norway court finds him sane', BBC News, 24 August 2012: http://www.bbc.co.uk/news/world-europe-19365616.

Optional Exercise C: What are the respective roles of criminal law and mental health professionals in a case such as this? What do you think marks the distinction between someone who has a mental illness and someone who simply chooses not to comply with the law? How differently do you think such a case would be dealt with in your country?

an "Insanity"/"not responsible due to mental disability" defence is a soft option. Moreover, issues such as lack of adequate public mental health facilities, the proliferation of nuisance laws capturing mentally disordered persons within their scope and prison conditions occasioning or failing to prevent the onset of mental ill health mean that the number of mentally disordered persons among prison populations is high. Thus, a 2002 review of 62 surveys from 12 western countries found that prison inmates were several times more likely to have psychosis and major depression, and about ten times more likely to have an antisocial personality disorder, than the general population; 65% of male prisoners and 42% of female prisoners were found to be suffering from a personality disorder (Fazel,S., and Danesh, J., 'Serious mental disorder in 23 000 prisoners: a systematic review of 62 surveys', The Lancet, 2002, Vol.359, Issue 9306, available at: http://www.thelancet.com/journals/lancet/article/PIISO140-6736(02)07740-1/fulltext).

The WHO has highlighted the need to try to divert criminal offenders with mental disorders away from the criminal justice system (whose focus on deterrence and punishment is arguably inappropriate in meeting the needs of such persons), and into the mental health care system. Such diversion can take place at a variety of stages in the criminal process:

- 1. **Through pre-trial decisions** to forego prosecution in favour of voluntary treatment for offenders posing no serious risk to the public
- 2. Via a mental health assessment finding that an accused person is not fit to stand trial and should be transferred to a mental health facility for treatment until he becomes so fit
- 3. **Through a finding** that an accused person is not responsible on grounds of his mental disability, which may result in release or an order for admission or treatment; or
- 4. At the sentencing or incarceration stage where an accused has not met the legal criteria for a defence based on mental disorder but it is nevertheless recognised that he has mental health care and treatment needs, or where mental disorder has developed after his incarceration.
- * WHO Resource Book on Mental Health, Human Rights and Legislation, 2005, pages 75-80: http://www.who.int/mental health/policy/who rb mnh hr leg FINAL 11 07 05.pdf

Exercise 4.2: Watch the following Frontline documentary, *Imprisoning the Mentally III – The Asylums* 2005 (1 hour video in 5 parts). The documentary canvasses how the closure of mental health facilities led to a significant rise in the number of persons with mental disability in the US penitentiary system and the impact of this on mentally ill persons. Please note that the first half of parts 2 and 3 of the video show scenes of violence and distress. We recommend watching the full video though viewer discretion may be applied in these parts.

Imprisoning the Mentally III – The Asylums 2005 (1 hour video in 5 parts):

http://www.youtube.com/watch?v=UPTSFGPxew8&feature=related

http://www.youtube.com/watch?v=iU1y3KFUy7E&feature=reImfu

http://www.voutube.com/watch?v=QgimvvcXJ5w&feature=reImfu

http://www.youtube.com/watch?v=4GvdQQHYHmM&feature=relmfu

http://www.youtube.com/watch?v=TaMm0XfBq_w&feature=relmfu

If your internet connection does not allow you to watch this video please read:

'Mental Illness, Human Rights, and US Prisons', 2009 Human Rights Watch statement for the record to the Senate

Judiciary

Committee:

http://www.hrw.org/sites/default/files/related material/Human%20Rights%20Watch%20Statement%20fo

r%20the%20Record 9 22 09.pdf

Post your thoughts on one or more of the following and respond to the thoughts of others:

- 1. What public sectors and services need to be addressed to tackle the problem of incarceration of persons with mental disability in the US penal system? What should be the respective roles of the criminal justice (courts, police prosecutors) and penal (prisons, parole boards, and parole supervision) systems and mental health care services?
- 2. How might one justify increased expenditure on keeping mentally ill people out of prisons?

Component 2: Human rights and mental disability

4.2.1. The significance of international human rights law to persons with mental disability

International human rights law (IHRL) provides a framework for State action concerning persons within its territory. In the mental health context it provides a broad framework for the formulation and implementation of mental health law and policy. International human rights law was borne of an attempt to guard against the considerable abuses committed by States against their own citizenry in the period up to and during World War II. It forms a major part of the UN's mandate.

IHRL's significance to persons with mental disabilities is considerable:

Human rights obligations are underpinned by universally recognised moral values that have human dignity at their centre. This makes them a powerful tool to protect the rights of mentally disabled persons by making strong moral and legal claims that can be used in advocacy and lobbying through political, legal and quasi-legal mechanisms. The normative/moral basis of these rights means that they cannot be stripped away by ordinary political processes due to prejudicial public perception – they are possessed by virtue of a person's membership of the human race and can only be limited to the extent necessary and proportionate to any legitimate justification for such a limitation.

Also, with its emphasis on non-discrimination, IHRL particularly highlights the need to protect those most vulnerable to abuse; that persons with mental disability are some of the most vulnerable individuals in society is beyond dispute. Thus, even in developed countries with advanced democratic and constitutional systems, human rights law is instructive where, for example, law or its application has a discriminatory impact on mentally disabled persons. Moreover, it is increasingly recognised that human rights realisation and non-discrimination are an important part of poverty reduction efforts in any state.

For information on human rights based approaches to poverty reduction in the context of the right to health see *Impact Assessments, Poverty and Human Rights: A Case Study Using The Right to the Highest Attainable Standard of Health* by Paul Hunt and Gillian McNaughton, available at: http://www.ifhhro.org/images/stories/ifhhro/documents-un-special rapporteur/3-4-21.pdf

Thirdly, at the centre of IHRL is a call for accountability. Particularly regarding economic, social and cultural rights, which include the right to mental health, IHRL demands that state policy making processes engage those they are intended to benefit. Thus they should be formulated, implemented and monitored with transparency, participation and in accordance with a national plan that contains clear goals. IHRL therefore addresses a country's management of its resources, including a growing scholarship on the obligations of developed states to provide international assistance and cooperation to less developed states to help them meet their human rights obligations. Again, evidence that the mental health sector is often one of the most underfunded fields in national health care provision is overwhelming. IHRL provides oversight mechanisms that subject State action to scrutiny at several levels.

For further information on the duty to provide and seek international assistance and cooperation read paragraphs 17 to 30 of the UN Special Rapporteur on the Right to Health, Paul Hunt's Report Addendum: Missions to the World Bank and the International Monetary Fund in Washington, D.C. (20 October 2006) and Uganda (4-7 February 2007) 2008, available at: http://www.unhcr.org/refworld/type,MISSION,,UGA,47da904c2,0.html.

For information on the role of accountability in achieving the right to the highest attainable standard of physical and mental health, including examples of its application, see Potts, H., *Accountability and the right to the highest attainable standard of health*, 2009, University of Essex, available at: http://www.equalinrights.org/library/resource/resource/accountability-and-the-right-to-the-highest-attainable-standard-of-health-1/

For information on how corruption can violate the right to the highest attainable standard of health see pages 45 to 49 and 51 to 55 of *Corruption and Human Rights: Making the connection*, 2009, IHCHRP and Transparency International, available at: http://www.ichrp.org/files/reports/40/131 web.pdf

Finally, IHRL has begun to engage with the role of non-state actors such as private hospitals, pharmaceutical companies and international financial institutions. The policies and actions of these entities can have considerable implications for the lives of mentally disabled people and their ability to obtain available, acceptable and quality health care and treatment.

For information on the right to health and pharmaceutical companies please see the Annex to the UN Special Rapporteur on the Right on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health report, which contains the *Human Rights Guidelines for Pharmaceutical Companies in relation to Access to Medicines*, available at: http://www.who.int/medicines/areas/human rights/A63 263.pdf

For information on the role of the World Bank in assisting members to fulfil their human rights obligations see the *Legal Opinion on Human Rights and the Work of the World Bank* issued in 2006 by World Bank former Senior Vice-President and General Counsel, Roberto Dañino; or 'The Legal Aspects of the World Bank's work on Human Rights' in 41 *International Law* 21 (2007), Roberto Dañino, available through Heinonline Law Journal Library via Edinburgh E-Journal catalogue.

For these reasons the Global Mental Health Movement has placed human rights realisation at its centre, a goal further supported through the work of international agencies such as the WHO and the PAHO.

4.2.2. The human rights obligations of states regarding persons with mental disability

a. The framework of State obligations under human rights law

Although expressed in separate treaties it is now well recognised that civil and political rights and economic, social and cultural rights are interrelated, interdependent and indivisible, and that both of these types of right impose corresponding obligations on states to respect, protect and fulfil rights. Respecting rights requires states to refrain from interfering with rights, e.g. by arbitrarily detaining people or subjecting them to inhumane and degrading treatment. The obligation to protect rights requires states to regulate how state and non-state parties engage with a right holder's rights to ensure that such rights are not violated, e.g by criminalising the abuse and exploitation of vulnerable persons. The obligation to fulfil

rights requires that states take active steps to put in place institutions and procedures, including the allocation of resources to enable people to enjoy their rights. This positive obligation moves beyond state restraint and the mobilisation of traditional legal mechanisms to engage with the crucial role of state policy in rights realisation and enjoyment.

* 'Guide to the use of International Human Rights Law' at pages 10 to 19 in *The Role of International Human Rights in National Mental Health Legislation*, 2004, Department of Mental Health and Substance Dependence, WHO. Available at: http://www.who.int/mental-health/policy/international-hr-in-national-mhlegislation.pdf

b. Regional human rights systems

Human rights systems have also developed regionally. development of regional human treaties allows rights state obligations to be interpreted in a appropriate manner regional context and, crucially, has allowed for the development of regional enforcement mechanisms that are increasingly gaining regional strength. These mechanisms are very important to understanding the interpretations of rights in the country context though it should also be noted that some systems are more highly developed than others. Thus for

Inhumane treatment in Ecuador: Victor Rosario Congo v Ecuador was the first mental disability rights case in the Inter-American human rights system. Here, a person with mental disabilities had been detained in a Social Rehabilitation Center after being charged in a criminal case. After failing to cooperate with questioning Congo was beaten and left by staff in an isolation cell naked and virtually incommunicado. He remained without treatment for his injuries for forty days and was eventually taken to hospital to treat severe hydration but later died. In this landmark case the American Commission found that special standards apply when analyzing rights under the American Convention regarding persons with mental disability and that the MI Principles (see below) should guide the determination of humane treatment. It emphasised that violations of the right to physical integrity are even more serious when perpetrated against persons with mental disability held in custody, due to their particular vulnerability. Available at:

http://www.cidh.oas.org/annualrep/98eng/Merits/Ecuador%2011427.htm.

example, the Inter American Human Rights Commission, which forms part of the judicial architecture of the Inter-American Human Rights system has looked to the more developed European Human Rights system for authoritative guidance on the interpretation of human rights in the context of mental disability.

European landmark for those is social care: The European human rights system has developed a considerable jurisprudence on the rights of persons with mental disability. In a landmark decision in January 2012 the European Court of Human Rights forged new ground in its case law and asserted the obligation on states to end policies and practices that unnecessarily restrict the liberty of thousands of persons with psycho-social and intellectual disabilities in the provision of social care in *Stanev v Bulgaria*.

Rusi Stanev, was placed under partial guardianship in 2000 and sent to a social care institution by his guardian in 2002. He has never been able to legally challenge either of these measures in domestic courts. In his application to the European Court, he complained of this lack of access to justice as well as his subjection to deprivation of liberty, restrictions on his right to a private life and of ill-treatment due to the terrible conditions in the social care institution. The Court found a violation of Article 5(1) (right to liberty and security of person) of the European Convention on Human Rights (ECHR), finding that Stanev could be considered to be "detained" in a social care

institution, the first time that the Court has made such a finding. As Mr. Stanev was legally unable to challenge or seek compensation for his detention, Articles 5(4) and 5(5) of the ECHR were also violated. The Court unanimously held that Mr. Stanev had also been subjected to degrading treatment in violation of Article 3 (freedom from torture and cruel, inhumane and degrading treatment) by being forced to live for more than seven years in unsanitary and unliveable conditions, without a remedy for these violations in the domestic courts. This is the first case in which the Court has found a violation of Article 3 in a social care setting. The other major issue raised in the case was how the law prohibited Mr. Stanev from challenging restrictions on his legal capacity. Having been placed under partial guardianship, under Bulgarian law Stanev needed his guardian's consent to initiate such a proceeding, a fact that the Court unanimously found to be a violation of his right to a fair trial under Article 6 (right to a fair trial) of the ECHR. In this regard, the Court referred to the growing emphasis that international law places on the legal autonomy of persons with disabilities, stating that it "is also obliged to note the growing importance which international instruments for the protection of people with mental disorders are now attaching to granting them as much legal autonomy as possible" (para.244).

Stanev v Bulgaria, European Court of Human Rights (Grand Chamber) Decision of 17 January 2012, Application No. 36760/06, available at:

 $\underline{http://hudoc.echr.coe.int/sites/eng/pages/search.aspx\#{"dmdocnumber":["898586"],"itemid":["001-108690"]}$

- * Gostin, L., and Gable, L., 'The Human Rights of Persons with Mental Disabilities: A global perspective on the application of human rights principles to mental health' 63 Maryland Law Review 20 (2004), pages 47-55, available from http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1435443
- * Section 6.1.2 in WHO Resource Book on Mental Health, Human Rights and Legislation, 2005, pages (pages 11 to 13): http://www.who.int/mental health/policy/who rb mnh hr leg FINAL 11 07 05.pdf

For further information on regional human rights systems and how they have interpreted the rights of persons with mental disability see the additional references document.

c. Thematic treaties

The human rights expressed in the international bill of rights have been further elaborated on in thematic human rights treaties. These include treaties on specific rights violations such as the Convention against Torture and other Cruel, Inhumane or Degrading Treatment or Punishment, as well as treaties addressing specific groups of persons vulnerable to particular types of rights violations including women, children, migrant workers and persons with disabilities (see below). It is important to note that those with mental disability can be subject to multiple forms of discrimination, which may result in specific forms of rights violation. Thus law under all of these treaties will be relevant to the needs of individuals with mental disability in accordance with their status and situation.

For further see:

- 1. International Convention on the Elimination of Racial Discrimination 1965, Article 5.
- 2. International Convention on the Elimination of Discrimination Against Women 1979, Articles 11,12

Optional Exercise D: List five conventions applicable to persons with mental disability in your country of origin. You may wish to check which treaties your country has ratified via the UN Treaty Series: http://treaties.un.org/Pages/Treaties.aspx?id=4&subid=A&lang=en.

d. Application of human rights treaties in a mental health context

Lack of specific provision under existing human rights treaties means that many human rights standards explicitly addressing the rights of persons with mental disability have developed through what are called soft law instruments. Whilst these instruments are not binding in and of themselves, they nevertheless represent authoritative interpretations of how the rights of mentally disordered persons should be realised in context. These standards have been developed at both international and regional levels.

The following are some of the most important international soft law instruments:

Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (MI Principles) 1991 –

These principles are considered one of the most detailed international standards for persons with mental disabilities. They provide guidelines for the establishment and evaluation of national mental health systems and offer an interpretation of general human rights norms in the mental health context. They have been endorsed as authoritative by human rights mechanisms and used as a model for mental health legislation and a guide for reviewing and recasting mental health policies and restructuring mental health services. They assert the right of persons with mental disabilities to the fundamental freedoms expressed in human rights conventions and outline the most important rights for persons with mental disabilities, which include the right to medical care, the right to be treated with humanity and respect, the right to equal protection, the right to be cared for in the community, right to provide informed consent before receiving any treatment, the right to privacy, freedom of communication, freedom of religion, the right to voluntary admission, and the right to judicial guarantees. It should be noted that whilst progressive at the time of their adoption, these principles have since been criticised for affording weaker protections than other international instruments, particularly in respect of the right to refuse treatment under Principle 11.

As such reference to other regional standards such as the Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine 1997, may also be instructive. Indeed, technical standards like the WHO's Mental Health Care Law: 10 Basic Principles (available at: http://www.who.int/mental health/media/en/75.pdf) have also been adopted to act as a tool for the further interpretation of the MI Principles, whilst its Guidelines for the Promotion of the Human Rights of Persons with Mental Disorders (available http://www.who.int/mental health/policy/legislation/guidelines promotion.pdf) are also intended as a further interpretive tool to evaluate the human rights situation in institutions and assist in drafting new mental health legislation.

Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules) 1993 –

The Standard Rules set out guidelines for implementing the basic rights and fundamental freedoms under international instruments, for persons with disabilities. The Standard Rules are applicable to persons with mental disabilities though they do not systematically address the rights and needs of such persons. Nevertheless, they compliment the MI Principles in providing guidance on the active participation of persons with mental disability not addressed in the Principles. These Rules assert the rights of people with mental disabilities and their organizations, to participate in drafting new legislation on issues affecting them. Governments are expected to provide significant and actual (rather than symbolic) facilitation of this involvement. Thus, the Rules envision a degree of involvement that ensures that the voices of persons with mental disabilities are fully heard in the process. According to the Rules, people with mental disabilities, their families, and community advocates should be included in the planning, design, implementation, and evaluation of services, support, and oversight programs. Moreover they emphasise that "States should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society". The Standard Rules differ from the MI principels to the extent that they provide for a Special Rapporteur and enforcement committee to oversee their implementation, which has allowed for both their further development and greater openness and information sharing in respect of compliance.

Available at: http://www.un.org/esa/socdev/enable/dissre00.htm

Committee on Economic Social and Cultural Rights, General Comment 5 (1994) on the rights of persons with disability -

This comment provides authoritative guidance on state obligations under the International Covenant on Economic, Social and Cultural Rights in respect of persons with disability. It endorses the Standard Rules, the MI Principles and the 1990 Guidelines for the Establishment and Development of National Coordinating Committees on Disability or Similar Bodies. It emphasises the obligation on states to take positive action to reduce structural disadvantages and to give appropriate preferential treatment to people with disabilities to achieve their full participation and equality, including through appropriate resource allocation and the regulation of non-state actors to ensure that they too respect the rights of persons with disabilities. It stresses that while Governments may rely on private, voluntary groups to assist persons with disabilities, such arrangements cannot absolve states of their treaty obligations. These duties include the need to ascertain, through regular monitoring, the nature and scope of the problems faced by disabled persons within the State; the need to adopt appropriately tailored policies and programmes in response; the need to legislate where necessary and to eliminate any existing discriminatory legislation; and the need to make appropriate budgetary provisions or, where necessary, seek international cooperation and assistance. The comment emphasises that international cooperation under articles 22 and 23 of the Covenant is likely to be a particularly important in enabling some developing countries to fulfil their obligations under the Covenant. Much of the content of the comment is now binding through the Disability Rights Convention (see below).

Available at: http://www.un.org/esa/socdev/enable/dissre00.htm

Committee on Economic Social and Cultural Rights, General Comment 14 (2000) on the right to the highest attainable standard of physical and mental health –

This general comment outlines the overall framework of the right to the highest attainable standard of physical and mental health under Article 12 of the ICESCR. It highlights that the right to health extends to

the underlying determinants of health such as water, food and sanitation and the right to participate in health related decision making. The comment emphasises that health facilities, goods and services must be assessed in terms of their availability, accessibility (physically, financially and in a non-discriminatory manner), acceptability (e.g. compliant with medical ethics) and quality. The comment notes that the concept of progressive realisation recognises that resources are not limitless and that governments cannot be expected to do more than make the best of the resources available to them. However, it also underlines that some obligations under the right to health are immediate including ensuring nondiscrimination in the availability, accessibility, acceptability or quality of healthcare and the underlying determinants of health, as well as taking deliberate, concrete and targeted steps towards the full realisation of the right to health. As such, the core minimum obligations which each state should strive to meet at a minimum are non-discriminatory access to healthcare, especially for vulnerable and marginalised groups, the provision of essential drugs as defined under the WHO Programme of Action on Essential Drugs and equal distribution of health facilities, goods and services. Crucially, it also includes the adoption and implementation of a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population, which is devised and periodically reviewed using a participative and transparent processes, paying particular attention to vulnerable or marginalised groups. This includes using methods such as disaggregated right to health indicators and benchmarks by which progress can be closely monitored. The comment highlights that violations of the right to health can be perpetrated by acts of omission such as failure to take appropriate steps towards rights realisation for all or to enforce relevant laws. General comment 14 recognises the MI Principles as a obligations the Convention.. Available guide state under from: http://www.unhcr.org/refworld/pdfid/4538838d0.pdf

- * WHO Resource Book on Mental Health, Human Rights and Legislation, 2005, pages (pages 13 to 17): http://www.who.int/mental health/policy/who rb mnh hr leg FINAL 11 07 05.pdf
- * 'Major UN Human Rights Standards' at pages 24 to 26 in The Role of International Human Rights in National Mental Health Legislation, 2004, Department of Mental Health and Substance Dependence, WHO. Available at: http://www.who.int/mental_health/policy/international_hr_in_national_mhlegislation.pdf

Human rights in Focus: The right to the highest attainable standard of health

Together, the above soft law instruments flesh out the content of the right to the highest attainable standard of physical and mental health through a series of ancillary rights and principles applicable specifically in a mental health context. These include the right to individualised treatment and the principle that treatment should be geared towards rehabilitation and the enhancement of the autonomy and skills of each individual. In asserting the right to independence and social integration the principle of providing services that are the least restrictive alternative for treatment is built into human rights approaches to physical restraint and involuntary seclusion, including through procedural safeguards. Moreover, the right to receive treatment and care as far as possible in one's own community emphasises the need to incorporate community based services into national mental health planning and budgeting. The principle of informed consent and the right to refuse treatment also have a

significant bearing on provision made for those lacking legal capacity and the procedures put in place to for determining this status. Moreover the overarching obligation to ensure non-discrimination can require health policies to reassess their use of institutionalisation and guardianship.

* Pages 26-46 in *The Role of International Human Rights in National Mental Health Legislation*, 2005, Department of Mental Health and Substance Dependence, WHO. Available

http://www.who.int/mental health/policy/international hr in national mhlegislation.pdf

Exercise 4.3

Post your thoughts on some of the challenges there might be to implementing the right to health in your own country, with reference to specific aspects of that right? If possible, respond with thoughts on how one might start trying to address challenges posted by others

4.2.3. The human rights of persons with disability

Despite the universal applicability of human rights, persons with disability have continued to suffer widespread and severe human rights violations. The Convention on the Rights of Persons with Disabilities is a response to this fact and has served to mobilise reform efforts regarding provision for those with mental disabilities. The Convention represents a major attitudinal shift from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing them as "subjects" with rights. The Convention came into force in 2008 and seeks to promote, protect and ensure the full and equal enjoyment of the human rights of people with disabilities and to ensure respect for their inherent dignity. It builds on previous international instruments related to persons with disabilities, including 1994 Standard Rules on the Equalization of Opportunities for Persons with Disabilities. As such, it does not create new rights but clarifies the existing human rights framework as it applies to persons with disability in the form of a binding legal document. This document is both a human rights law instrument and development policy document.

The Convention and its provisions are founded upon eight general principles:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- 2. Non-discrimination
- 3. Full and effective participation and inclusion in society
- 4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- 5. Equality of opportunity
- 6. Accessibility
- 7. Equality between men and women
- 8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

The Convention emphasises the need for international cooperation, including for international development programmes to be inclusive of, and accessible to, persons with disabilities, as well as the need to mainstream disability into all development activities (recognising that disability specific measures may be necessary to 'accelerate or achieve de facto equality of persons with disabilities') and human rights mechanisms.

The treaty's implementation is overseen by the Committee on the Rights of Persons with Disabilities, which receives reports from Member States about actions they have taken to promote the rights of people with disabilities. States ratifying the Convention's Optional Protocol also empower the Committee to hear complaints about rights violations under the convention from individuals or groups. It may also conduct inquiries into such violations. The Convention is further supported by the work of the United Nations Inter-Agency Support Group for the Convention on the Rights of Persons with Disabilities (IASG) and the Special Rapporteur on Disability.

Convention on the Rights of Persons with Disabilities 2006, Articles 1-23, 25, 26, 28, 32 and 33, available from: http://www.un.org/disabilities/default.asp?id=150

Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for human Rights Monitors, Office of the High Commissioner for Human Rights, 2010 (recommended reading in your own time for skills development): http://www.ohchr.org/Documents/Publications/Disabilities training 17EN.pdf.

United Nations handbook for parliamentarians on the Convention on the Rights of Persons with Disabilities, UN, OHCHR, IPU, 2007: http://www.ipu.org/PDF/publications/disabilities-e.pdf

As a participating agency on the IASG the WHO has taken various steps to facilitate States in implementing the Convention including through the launch of its 2011 World Report on Disability, the establishment of a Task Force on Disability and the mainstreaming of the rights of people with disabilities throughout its technical programmes. As part of this action the WHO has launched the QualityRights Project and Toolkit, which seeks to improve quality and human rights conditions in mental health and social care facilities and empower civil society organizations to advocate for the rights of people with mental and psychosocial disabilities. The QualityRights Toolkit aims to assist states to assess and improve quality and human rights standards in their national facilities on the basis of the ICRPD.

The toolkit establishes key standards that must be met in all facilities, including the need for:

- Living conditions to be safe and hygienic and the social environment to be conducive to recovery;
- The provision of evidence-based care for peoples' mental and physical health condition, on the basis of free and informed consent;
- Gearing services towards enhancing people's autonomy enabling them to engage in their own recovery plans;
- Reporting and halting all inhuman treatment; and
- Linking health services with employment, education, social and housing services in order to promote independent living in the community for mental health service users.

This week's discussion



INDIVIDUAL ASSIGNMENT

You are a civil servant with the Ministry of Health in your country. You have been asked to put together a 500 word briefing on the implementation of the WHO QualityRights toolkit in your country for the minister:

- a) Briefly outline one of the CRPD's five themes covered by the toolkit, which you believe your country needs to improve and why.
- b) Give four international instruments (treaty and soft law) applicable to your country that cover this theme. (You may make reference to specific article/paragraph numbers in the footnotes, which will not count towards word count provided they only contain provision numbers)
- c) Give any government departments, and professional or consumer stakeholder groups in your country that you know of, whom the minister may wish to engage in addressing this theme.

Component 3: Advocacy

5.3. The role of advocacy in securing the rights of persons with mental disability

Advocacy structures in Ghana: NGOs such as Basic Needs and MindFreedom, and other mental health stakeholders in Ghana have begun to take steps to support and empower persons with mental disability including through the establishment of self-help groups, awareness raising initiatives and government lobbying. These steps have begun to reach peoples everyday lives and attract attention on the political landscape.

Basic Needs Ghana, 'Activities of Community Self Help Groups in Ghana' Parts 1 & 2: http://www.youtube.com/watch?v=ZDkKi6-TwLg&feature=relmfu and http://www.youtube.com/watch?v=GqL9zhmMNaw&feature=relmfu.

MindFreedom Ghana: http://www.youtube.com/watch?v=yYAJ4n8A7ZQ and http://www.youtube.com/watch?v=MM7XZMvc-hU&feature=relmfu.

Throughout this module the role of advocacy has been a pervasive undercurrent. Its utility is apparent in legal procedures and policies aimed to protect the rights of persons with mental disability and it has

been crucial to efforts to improve the lives of such persons on a policy level through awareness raising and lobbying work. Advocacy presents itself as a means of challenging discrimination experienced by mental health service users who might otherwise not be taken seriously or be ignored in contexts that affect them. By allowing persons with mental disability to speak out and express their views in processes affecting them on a personal and political level, to access information, to defend their rights and to explore their choices, advocacy is essential in securing the social inclusion of both persons with mental disabilities and their families, allowing persons with mental disability to secure their autonomy. As such, advocacy forms one of

11 areas for action in any mental health policy and has been a major force behind the improvement of services and development of mental health law and policy.

It is important to appreciate that there are many different kinds of advocacy which will be more or less appropriate for those experiencing mental disability depending on the situation they are faced with. For example, crisis advocacy, citizen advocacy, legal advocacy and 'best interests' advocacy all represent very

divergent approaches to supporting those with mental disability in their everyday lives. Moreover, some persons may need more than one type of advocate, e.g. where someone has engaged a crisis advocate due to mistreatment in a care context which gives rise to a legal claim and

Self-help advocacy in Santa Barbara: Self help mental health advocacy group, the Consumer Advocacy Coalition, has fostered links with the media and sought to engage the broader community in discussing the impact that budget cuts has had on service users and increase awareness about mental health and the importance of mental health services for individuals and wider society. In doing so this advocacy group has actively sought to align its efforts with those most vulnerable to resource deficiency in its county.

KEY-T3's "News in Focus", 'Mental health advocates involve community', http://www.youtube.com/watch?v=zPyAEpVy3IQ&feature=related

highlights the need for a more long term advocacy to reduce the isolation occasioning that individual's vulnerability to mistreatment.

Third Party Advocacy in New South Wales: As people with mental disabilities can be vulnerable to unfair treatment and require assistance in defending their rights Disability Advocacy in New South Wales assists both those with disability and their carers through a combination of strategies and services including education, professional advocacy and policy advocacy. In doing so it helps individuals to obtain fair treatment from in a range of sectors.

Disability Advocacy New South Wales case studies video, 'Disability Advocacy: giving people with a disability a fair go', http://www.youtube.com/watch?v=vEq8eRuTsdg&feature=related

- * Advocacy for Mental Health (Mental Health Policy and Guidance Package), WHO, 2003, pages 2 to 7, available at: http://www.who.int/mental health/resources/en/Advocacy.pdf
- * The Mind Guide to Advocacy, 2010, pages 2 to 9, available at:

http://www.mind.org.uk/assets/0001/7329/Mind guide to advocacy 2010.pdf

Optional Exercise E: What types of advocacy would be appropriate in the following cases and why?

Case study 1: Delphine is a 20 year old woman with a learning disability who has been detained by the police after being caught stealing from a shop. The police have agreed not to press charges this time. Delphine lives alone and is visited two times a day for food and care by a local care worker. Delphine says that the care worker is often rude to her and

sometimes brings other people to the house and talks about her as if she is not there. Delphine says that she did not want to upset the shop keeper by taking the items from the shop but that she had been told to take them by a friend. Delphine refuses to stop seeing this friend. She says that he is the only friend she has and he sometimes lets her go to his house.

Case study 2: Arthur is a 46 year old man who has been admitted as an in-patient in hospital after his family abandoned him because they could no longer manage his mental health problems. Three doctors come and see Arthur. They discuss his case and how best to treat him. Arthur is frightened, upset and confused. He knows he needs treatment but he does not understand why he has to stay at the hospital and wants the doctors to let him go home. This is making him aggressive towards staff.

Case study 3: Fatima was been a victim of severe long-term domestic abuse. This eventually led her to escape and move to a foreign country where she could not be found by her abuser. As a result of Fatima's experiences she suffers from serious PTSD and depression and has been attending a local clinic for medication. One day at the clinic Fatima appears to be behaving unusually. When one of the clinic's nurses speaks to Fatima, Fatima tells the nurse that she has two young children who were taken into care shortly after their arrival some years ago. Fatima says that the children were taken away after one of the children's teachers found out about her mental health problems. Fatima insists that she has never abused her children but that they witnessed her being abused by her ex-partner. Fatima says that she has now been told by the authorities that they wish to put the children up for adoption. She says she has always felt that there is nothing that she can do about the situation with her children because she is foreign and the authorities just think she is crazy and abusive.

Exercise 4.4

Think back to the clip of human rights activist, Gabor Gambos (http://www.youtube.com/watch?v=xrhwt-JmqLw). Post your thoughts on one of the following questions and respond to the thoughts of others:

- 1. How might the fact that Gabor Gambos is both himself a psychiatric survivor and a family member of someone who died in psychiatric care affect his ability to advocate in this field?
- 2. How might the government or health care providers support the work of advocates like Gabor on improving public health interventions for persons with mental disability?

In summary

Having studied this module you should now have an overview of the role of law in mental health service provision and the lives of persons with mental disability. We have touched on a shift in trends in national mental health legislation since the mid twentieth century, looked at the significance of definitions of mental disorder in legislating health interventions and canvassed the provision that specific mental health legislation can make for persons with mental disability. We have also addressed some of the challenges that mental disability can pose to traditional systems of criminal justice and seen how criminal justice and mental health service provision can interact. In addition, this module has sought to increase your understanding of the significance of international human rights law to persons with mental disability. This includes both how human rights law has been interpreted in respect of this group and some of the challenges it poses, as well as tools provided to states with a view to trying to meet some of these challenges. Finally, we have addressed the crucial role of advocacy in improving the lives and treatment of persons with mental disability. It is hoped that your greater awareness of these aspects of the interface between law and mental disability has enhanced your understanding of the multidisciplinary nature of mental health service provision, enabling you to draw on a wide range of resources in your future endeavours in this field.