



Draft Code of Practice for the guidance for persons  
working in Mental Health Service with People with  
Intellectual Disabilities:  
Consultation findings

**February 2009**

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## Executive Summary

The introduction of a code of practice on guidance for persons working in mental health services with people with intellectual disabilities and mental health problems was broadly welcomed by those who returned submissions in this consultation exercise. Such a code of practice is viewed as a further measure to protect the interests and rights of, what is seen by many working in the field as, a vulnerable population. One of the key themes emerging from submissions related to the scope of this document which many felt as it stands remains unclear. Respondents called for greater clarity in relation to what services this code of practice will apply to, whether it is mental health services, intellectual disability (ID) services or both. A small number of submissions called for emphasis to be placed on the complexity of diagnosis inherent in people with ID and mental health problems and also the fact that the level of ability of an individual can impact on the care and support required by that person.

Despite the aim of the code being to protect and safeguard the rights of persons with disabilities and mental health problems, a focal concern expressed in a small number of submissions related to whether this draft code would in fact create a two tier system in relation to restrictive practices and, in particular, seclusion, with a higher standard required in relation to such practices in approved centres and a lesser standard in non approved centre settings. There was a strong view in such submissions that the same standards should apply across the board. The point was also made in other submissions about reducing or eliminating the use of restrictive practices, particularly given the weak evidence base. This it was believed could be achieved by changing the culture and attitude towards service users in organisations as well as through identifying the cause of problem behaviours and focussing on preventative measures. The greatest number of suggestions for additions and changes to the section on restrictive practices pertained to psychotropic medication as restraint.

The importance of inter-disciplinary collaboration was iterated in a number of submissions with many suggesting the expansion of this section to further emphasise its importance. Lastly, a suggestion made in a number of submissions was that it would be helpful if reference was made to HIQA's draft standards for residential services for people with ID, and conversely that HIQA's standards make explicit reference to this draft code of practice.

## 1. Introduction

The Mental Health Commission was established under the Mental Health Act 2001. As determined by the Act [Section 33(1)], the principal functions of the Commission are “*to promote, encourage and foster the establishment and maintenance of high standards and good practices in the delivery of mental health services and to take all reasonable steps to protect the interests of persons detained in approved centres under this Act.*”

In line with its mandate, the Commission felt it appropriate to develop a code of practice for the guidance of persons working in mental health services with people with intellectual disabilities. People with intellectual disabilities and mental health problems have the same rights as the general population as espoused in both national and international legislation however these rights are not always respected and upheld. This code of practice aims to provide additional safeguards to help ensure that all persons with intellectual disabilities availing of a mental health service are afforded the rights to which they are entitled.

The Code of Practice has been prepared by the Commission in accordance with Section 33(3)(e) of the Mental Health Act 2001, whereby the Commission shall:-

*“prepare and review periodically, after consultation with such bodies as it considers appropriate, a code or codes of practice for the guidance of persons working in the mental health services”.*

## 2. Methodology

Key stakeholders were informed of the consultation between 17<sup>th</sup> September and 6<sup>th</sup> October 2008. For the full list of those contacted please refer to appendix 2. The NFVB and Inclusion Ireland agreed to assist the Commission in carrying out the consultation with their members. The Commission welcomed all methods of consultation in this exercise including focus groups, workshops, interviews and written submissions. Flexibility in the approach employed was considered important given the range of stakeholders likely to be involved in submitting feedback and in particular the likely input of service users. The consultation was also advertised on the Commission’s website for the duration of the process.

To help facilitate the consultation process, the Commission developed a “*Consultation Summary Guide*” which was provided along with the full draft code of practice (See appendix 1). The 10 page summary guide contained a summary of the draft code of practice and 4 specific consultation questions to help guide people in their feedback. Stakeholders were also advised that other feedback provided outside of these specific questions was acceptable.

The closing date for the consultation was 7<sup>th</sup> November 2008. However, anyone who requested an extension to the deadline was facilitated. The final closing date therefore was 23<sup>rd</sup> December 2008.

### 3. Findings

Twenty one submissions were received in total. Although the respondents were requested to provide information on the method of consultation used and the number of people represented by the feedback, not all submissions included this information. The submissions received therefore represent a minimum of 76 people, although the actual number is likely to be substantially higher than this.

Five specific questions were posed to facilitate feedback. Each of these questions is addressed in turn. Feedback that did not fall under any of these headings is dealt with in the other comments section to the end of the document.

#### 3.1 General Comments

Overall, the majority of respondents viewed the development of this code of practice as a welcome initiative, which goes towards ensuring that the needs of people with intellectual disabilities and mental health problems are well met.

*“a welcome addition to the literature and clinical guidance to people with disabilities, front line practitioners, advocates, carers and service providers drawing effectively for the most part on international and national expertise.”*

*“HIQA welcomes the opportunity to contribute to the development of this guidance. The document is clearly written and the content is likely to assist service providers and their staff to improve the service provided for people with intellectual disabilities”.*

*“The emphasis on the human rights of people with intellectual disabilities who are in receipt of mental health services is very much welcomed”.*

*“In the absence of mental capacity legislation, there is a great need for such a code of practice”*

*“We are particularly heartened and reassured by the recognition within the code of the vulnerability of this group, particularly the jeopardy of exposure to a range of restrictive practices.”*

*“I am confident that the Commission will find strong support within this organisation from all senior clinicians for your endeavours in relation to our vulnerable population”.*

Conversely the view asserted in one submission was that the document *“poses a very real threat for the provision of appropriate mental health services and the future mental health needs of people with an intellectual disability”* because it could *“be used as another instrument by health service management to further delay the role out of the services to this group laid down in government policy”.*

## 3.2 Specific Findings

1. Do you think the main areas of importance for people with mental illness and intellectual disabilities receiving care and treatment in mental health services have been identified in the draft code? If not, what other key areas would you include?

The majority of respondents felt that the main areas of importance were addressed by the draft code. One submission asserted that in particular key strengths of the document are the glossary, guiding principles, section on decision making and capacity, vignettes and referencing and bibliography. Another submission stated that it was positive to note that a person-centred approach is advocated and that the importance of communication is acknowledged.

There were a number of additional areas highlighted in submissions, which respondents felt necessitated some coverage. These were as follows:

One response suggested including a definition of the criteria for the **different levels** of intellectual disability, because this can create many variations in a persons capacity to consent and communication methods employed. Similarly, another submission stated that dependent on the level of ability of each individual, care and supports can be very different and therefore it is vital that this aspect of the requirements of people with ID is addressed. There is a danger that the specific needs of this client group relating to their ID will be overlooked within the guidelines. It would be helpful for the document to refer to the **complexity of diagnosis** inherent in people who have an intellectual disability and experience mental health problems. It was felt by some that the document did not focus sufficiently on the needs of this particular client group. Some behaviours can be defined as problematic rather than a symptom of an underlying mental health problem. People with an ID have specific health needs often attributed to particular syndromes e.g. prader-Willi or Lesch-Nyhan syndrome have very specific needs relating to management of problem behaviours. The guidance should address these specific needs.

Several respondents felt that the **scope** of the code was unclear. It was felt that the guidelines lack focus as to how they can be used in an ID setting. The draft code doesn't categorically state that it applies to ID services; it needs to make explicit the fact that anywhere where mental health treatment is provided falls under the remit of the Commission. It would be beneficial if it spelt out how it might be used as a frame of reference for services that are not mental health services as defined in the Act but which are dealing with mental health issues.

Greater clarity in relation to the **setting** in which people would be receiving care was called for by some; is it an ID setting or a mental health setting. The draft code does not describe what a mental health service for people with ID should look like.

This document fails to make specific a **service design** for this group. *“this document appears to relate to every service, from a typical group home where clients attend a psychiatrist to an approved centre under the mental health act, within this diverse array of placements the principles (as set out in the draft) appear to remain the same”* (1).

The view was expressed in one submission that there is a need to make explicit acknowledgement that there is a lack of specialised treatment units for certain people with ID. Another comment was that the document makes no reference to appropriate approved centres for people with intellectual disability when there is a necessity for them to be detained (1).

A useful suggestion in one submission was to clarify at the outset what the code is not- that the focus is firmly placed on how key professionals and stakeholders interact and collaborate and, that it does not intrude on the domain of clinical judgement of the individual professional bodies or the unidisciplinary codes of the professional regulatory bodies.

There was a strong view in three submissions that developing a code that addresses restrictive practices appears to create a **two tier system** with a high standard for approved centres with the Section 69 rules and a lesser standard within ID services. Furthermore, it was felt that some of the practices currently used in those services not governed by the MHA 2001 have no legal basis and therefore their use amounts to a serious constitutional breach. The view was expressed that *“no one shall be deprived of their liberty, save in accordance with the law”* (Article 40.4.1). There was a strong sense that the principles of best practice as laid down in Section 69 of the Act should apply to this group of service users and therefore this section of the draft code should be revised accordingly (3).

Other areas that some respondents wanted included in the code were as follows:

- include the importance of ensuring provision of appropriate and relevant communication with relevant others in the context of the service user’s journey onwards (1);
- the area of risk taking planning should be given more prominence in the document (1);
- the areas of mental illness prevention and promotion (1);
- include that access to mental health services is available in the least restrictive setting (1);
- important that the document distinguishes between first and subsequent episodes of restrictive intervention, first may be unplanned, further episodes should have planned response (1);
- strengthen nursing advice on restraint (1).

## 2. Are you happy with the guiding principles of the draft code?

Respondents were generally happy with the guiding principles of the draft code.

*“The guiding principles are clear and adhered to throughout the document”*

*“The guiding principles generally conform to international human rights standards”*

In relation to **best interests**, it was suggested that best interests could be described, including who can make a decision in the best interests of the person (2). One submission suggested omitting the best practice principle as they considered it at odds with the principle on presumption of capacity.

In relation to adopting a **person-centred approach**, protecting cultural and religious views of this client group should be identified as an important part of a person-centred approach (1).

In terms of **presumption of capacity**, it was stated that any code of practice in this area should acknowledge that everyone has legal capacity but some people need more support than others in exercising that capacity, and that such a code should focus on assisting people to make their own decisions.

*“The Law Reform Commission’s paper ‘Vulnerable Adults and the law’ will copper fasten the points made in section 4.3; this was seen as a positive”.*

It was suggested to include the meaning of the latter sentence in 4.3 which referred to the balance of probabilities *“This means that in order to displace the presumption of capacity, a person making the case that a person lacks capacity must show that it is more likely that the individual lacks capacity than that he/she has capacity in relation to the particular matter at issue”* (1).

One submission called for clarification on families authority to make decisions.

It was suggested in relation to **least restrictive** intervention to include the wording “in consistence with the legislation” (1).

Other principles that were suggested for inclusion were:

- Recovery (1)
- Advocacy (1)
- the four principles guiding Quality and Fairness should be the principles guiding those providing mental health services (1).



- the general principle in the Disability Convention of full and effective participation and inclusion in society be referred to in the principle on person centred approach (1).
- quality of care and treatment and the quality framework since it is part of the functions of the Commission (1).
- greater prominence to the principles endorsed by the Commission in national and international legislation as referred to in the appendix (1).

### **3. Are there points in the draft code that you think should be changed? If so, what changes would you make?**

A number of suggestions were offered in relation to where changes could be made in the draft code. These are addressed below under the relevant section of the draft code.

## **Glossary**

It was indicated that the relationship between “problem behaviours” and “challenging behaviours” should be clarified (1).

It was suggested to include the following sentence in the definition of psychotropic medication as restraint “this can take the form of regularly prescribed or intermittently dispenses psychotropic medication (PRN medication) (1).

Include abbreviation (MDT).

Include definition for mental health problems which is used throughout the document (1).

Describe the full range of mental health difficulties that might be encountered, from the psychological distress experienced by many people, to serious mental disorders and illnesses that affect a smaller population (A Vision for Change).

## **Scope**

It was suggested to include here that the code of practice may be useful to providers of ID services and note that a small number of services are also registered as approved centres (1). See also earlier comments.

## **Introduction**

It was suggested that reference be given to the fact that there has been an increase in the life expectancy of persons with an intellectual disability which has resulted in changing patterns of

morbidity and mortality and an increasing recognition of the general and mental health needs of people with an ID (1).

Specific mention should be given to the Mental Capacity Bill 2008 in the introduction where the legislation is being discussed.

It was also suggested to replace the sentence “services start moving in the right direction” to “continue moving in the right direction” (2).

Include full title of EPSEN Act i.e. Education of Persons with Special Educational Needs.

## **Governance Section**

This section should be strengthened to state that ultimate responsibility for governance lies with the CEO and board of the organisation (1). It should also prompt service providers to review their statements ethos and values to ensure they enshrine the guiding principles (1).

It was recommended that the language in relation to policies is strengthened from “hopes” to “should ensure” (1). It was proposed that the review of policies could be undertaken by an independent monitoring group (1). In addition to policies, services should also have documented specific procedures in relation to the use of restrictive practices. (1). It was suggested that having a national suite of policies might be useful in this regard.

*“The guidance on the **monitoring** of restrictive practices by a nominated review structure is welcomed”.* It was recommended that this committee is inter-disciplinary in nature and includes such professionals as an occupational therapist, a speech and language therapist and a consultant psychiatrist (2). It was requested that the role and function of this group be further explained. It was also suggested that the frequency of periodic reviews of restrictive practices should be specified in the code i.e. every 6 months was suggested (1).

In relation to staff **training and education**, the importance of understanding intellectual disability was highlighted and that all staff working in mental health services receive this training (1). It was suggested that training in relation to mental illness be incorporated into the code (1). It proposed that staff are trained on relevant human rights principles (1). It was also recommended that training in relation to violent or dangerous behaviour be altered from “reactive” strategies to “responsive” ones (1). It was suggested that a more extensive list of training elements relating to restrictive practices be included such as how to identify different stages of a crisis situation, how to appropriately respond to behaviours at any stage; verbal de-escalation strategies; limit setting; how staff attitudes impact on behaviour; precipitating factors/triggers to behaviour issues; safer use of restraints; signs of psychological or physical distress relating to restraint use (1). It was suggested that training should take place, at a minimum, on an annual basis (1).

**Inter-disciplinary collaboration** was felt to be a particularly important area by a number of respondents and it was felt that this section could be expanded. It was recommended that it

make reference to the need for partnership and exchange of expertise. Inter-disciplinary collaboration should be encouraged to ensure a smooth transition from one service to another and in relation to the development and roll out of protocols on restrictive practices. Assistance for agencies in developing robust protocols was desired by some. This would encourage uniformity of procedures and good practice across services (4). It was recommended that collaboration with habilitation and rehabilitation services for persons with disabilities takes place to ensure that health, employment, education and social services needs are met. A suggestion was also made that the key worker may be ideally placed to facilitate inter-agency collaboration (1).

It was requested that a timeframe is included for reviewing the code of practice.

## **Person-centred approach**

It was recommended including an introduction to figure 2 as not everyone may be familiar with the quality framework. Another suggestion was that figure 2 should follow the text on page 15.

In terms of adopting a **person centred approach** it was emphasised that the individual care and treatment plan is only one aspect of this.

It was felt that reference to developing an **individual care and treatment plan** is somewhat vague and requires clarification as the terminology overlaps with existing frameworks in ID services. The question was posed as to whether a mental health care and treatment plan is separate to existing holistic plans for individuals (2). It was emphasised that the plan is not only evaluated with the service user, but is also drawn up with the service user and that the person's family should be involved at all stages unless there is strong evidence that the person doesn't want this (2). It was felt that there is a need to specify how persons with ID are given access to individual care plans with some respondents feeling that an appropriate copy of the care plan should be provided to the service user taking cognisance of the individual's level of ability, and that measures should be specified in relation to how the person is assisted to contribute to the official record. It was suggested that parameters may need to be set in relation to the review and revision of the care and treatment plan (2). One submission queried whether a national policy has been devised to facilitate individual care and treatment planning. It was suggested having documented as the last bullet in 8.1.

It was felt that **assessment** (S8.2) should feature as the first point in Section 8 since it is the starting point for the delivery of quality person-centred care (1). In relation to 8.2 comprehensive assessment, it was felt that problem behaviours should feature as a separate bullet (1). It was recommended that the cultural background of the individual should also be taken account of in assessment (1).

It was suggested that the service user and relevant others should be informed of who his/her **key worker** is and that this is documented. (2). *"The identification of a key worker to facilitate implementation of the plan is a very beneficial suggestion"*. It was suggested that the service user and key worker sign the plan (1).

It was also suggested that clinicians should try to include a **mental health diagnosis** in individual care and treatment plan.

## **Communication Issues**

It was suggested changing the “why” in 9.4 to “the rationale” (1).

It was recommended including a point relating to a person’s understanding of the information given and documenting this (1).

It was felt that this section be strengthened by stating that the person should have access to an independent advocate.

It was suggested defining “behavioural support plan” which is referred to in the example of a communication passport (1) and defining biopsychosocial (1).

## **Environment**

In terms of environmental considerations, it was suggested that 10.1 should be more emphatic and state that all mental health treatment should be provided in the **least restrictive environment**, consistent with the person’s needs (and need to be cared for safely) (3).

10.2 should state that the **design** of the physical environment should offer maximum opportunity to maintain or improve mental and physical health status (1).

**Engagement in meaningful activities** should be designated as essential (2). It was stated that staff perceptions and attitudes create environments in which meaningful activities may be encouraged (1). It was recommended that additional details such as recreational and leisure activities, facilities for educational and vocational rehabilitation, facilities to purchase items for daily living and occupational facilities be included here (1). Clarity was requested over what is meant by the term “transitions” in this bullet (1). It was stated that adequate opportunities for exercise and nutrition should be available to ensure quality of life indicators are met (2).

It was recommended that a person be treated and cared for, as far as possible, in the community in which he/she lives, and that the environment should be as close as possible to that of the normal life of persons of similar age.

It was also proposed that this section include staffing levels and the skill mix of staff.

It was recommended that Section 10.4 includes provision for non verbal communication approaches such as sign language, picture exchange communication systems and easy to read forms in buildings ensuring that appropriate communication supports are provided (2).

## Decision making and Capacity

It was suggested that “unless proven otherwise” should be deleted from 11.1 as it is viewed as contrary to the UN Convention (1).

It is imperative that clear criteria exist for who makes decisions including the professional background and level of knowledge that such individuals have relating to ID. (1)

Clarification was requested by some respondents in terms of who carries out **assessments of capacity** (2). It was suggested someone who has established a positive and effective relationship with the service user may be best placed to do this (1). Conversely, another submission suggested it should be undertaken independently.

It was recommended that the code include a commitment to review when the new capacity legislation is in place (2).

## Considering the Use of Restrictive Practices

It was stated that the **lack of an evidence base** for the use of restrictive practices is of concern and poses the question of whether they should ever be used and in what context. It was also suggested that it might be appropriate to refer to the fact that there is evidence that some of these practices are potentially dangerous with both physical and psychological risks inherent in any use of restraint (2).

It was suggested that reference is made to changing the **culture** of services since changes in attitudes and practices towards service users can help reduce or eliminate the use of some restrictive practices. It was also suggested this section should be more holistic rather than being focussed on a behavioural model as it currently stands (1).

Concern was expressed over the use of the term “**problem behaviours**” (2). One view related to the classification of such behaviour as a diagnosable disorder. The point was made that many approaches to problem behaviours focus on environmental determinants. It was highlighted that 13.2. refers to “unsafe behaviour” whereas previously the term problem behaviours has been used (1).

A recurring issue was the need to ascertain the **cause of the problem** but the fact that the distinction between problem behaviours and mental health problems is not always clear was noted (and should be referred to in this document). It was suggested that a holistic approach to assessment and treatment should be employed. Another suggestion was to focus on the promotion of “positive behaviours”.

The Irish Human Rights Commission recommends that a provision is included in the code in relation to the impermissibility of using restrictive practices that intentionally or unintentionally deprive a person of his/her liberty (1).

It was suggested that the wording in 13.4 be changed from “highly undesirable” to “unacceptable”. (1)

A definition of immediate threat of serious harm to self or others was requested (1) and also the extent to which one can employ restraint in non urgent but very concerning situations.

### **Using Restrictive Practices (Sections 14-17)**

It was suggested that reference should be made to the recent recommendations in the Interim report of the **UN Special Rapporteur** on Torture, and other cruel, inhuman or degrading treatment or punishment (1).

It was felt by some that **all decisions** regarding the use of restrictive practices should be multi-disciplinary in nature and supported by the full team. Likewise the organisational committee tasked with periodically reviewing the use of restrictive practices should be inter-disciplinary (e.g. speech and language therapist, OT). It was recommended that the MDT individual care and treatment plan should identify a range of interventions to address the behaviour in the first instance (1).

It was recommended that the reasons for, nature and extent of any restrictive practice is included in the written record (1).

It was suggested that family, parent/ carer or chosen advocate should be informed of restrictive practices unless it can be proved informing them would have a detrimental impact on the person (1). It would be beneficial if an advocate or family member could be involved in 14.8, 15.7, 17.7 as many individuals may not be able to discuss the issue.

Further clarification on the nature of the assessments required in Section 14.4 and 15.3 was requested (1).

In relation to **mechanical restraint**, **physical restraint**, and **seclusion** it was suggested to include a written record that the communication referred to in 14.7/15.6/17.6 has occurred (1).

It was suggested that the definitions for mechanical restraint and physical restraint required further differentiation (1).

In relation to **physical restraint**, it was suggested that additional guidance is included such as no pain is involved; the intent is to calm the individual; the individual is not restrained on the floor or in a manner that would impede breathing; team interventions are used; restraint is never used as a method of punishment or for staff convenience (1).

It should be stated that **seclusion** is an emergency intervention and should never be part of a planned management strategy or written up as part of a behaviour plan. It was recommended that the code states that involuntary seclusion does not continue beyond the period strictly necessary in line with the MI Principles. More information on the nature and frequency of monitoring of seclusion was requested (1).

In relation to the section on **psychotropic medication** as restraint, several further specifications were recommendations. It was suggested that the adoption of a positive approach to behaviour, with particular emphasis on preventative measures should be the initial starting point with regard to the use of psychotropic medication and that the importance of preventative activity cannot be emphasised enough (1). Include “as restraint” after all instances of psychotropic medication (2). It was felt that ultimate responsibility for prescribing psychotropic medication should be determined by a medical practitioner, whether that be a consultant psychiatrist (CP) or nominated deputy such as a registered medical practitioner acting under supervision or deputising for a CP (1). It was believed that the MDT should be involved in this decision also with some suggesting that nurses are key stakeholders in this regard (1). It was also suggested that a pharmacist should be part of the MDT (1). It was suggested that the prescriber indicate the maximum 24 hour dose of any medication, whether the medication is “off license” and should consider other medications the person is taking. If the medication is “prn” information should be supplied by the prescriber and the use monitored. Its use should be regularly assessed. The outcomes of use should be objectively assessed. Withdrawing medication and exploring non medication options should be ongoing. It was pointed out that no reference is made to rapid tranquillisation or covert medication in the document. It was suggested the term “tranquillising” be removed from the definition of psychotropic medication (1). It was also suggested that the rationale for use should be explicitly documented. Also, the short- and medium-term outcomes should be included here. One response indicated that “psychotropic medication as restraint” was not the appropriate terminology although no alternative wording was suggested. In vignette 4 Siobhan’s key worker consents on her behalf. The point was made that this is not possible in Irish law and is confusing for the reader (3).

Additionally, guidance would be welcomed on urgent medical intervention following injury or in a situation where medical investigations are required.

It was recommended that **psychological restraints** and **technological surveillance** be included in the code such as where such technologies are designed to trigger other forms of restraint or seclusion. Technological surveillance such as tagging, pressure pads, CCTV and door alarms; *“these methods are increasing being included within an individual agreed plan of care, provided they operate within organisational policy, clear guidance and risk assessment”*(1).

#### **4. Are there points in the draft code that you think should be left out completely? Please identify these points and give a reason for your answer.**

Very few submissions felt that there were points in the draft code that should be omitted completely.

*“The document is well structured and comprehensive with regard to the pertinent issues”*

As previously highlighted a key contentious issue is that of restrictive practices. One response expressed concern about the fact that the restrictive practices section was the largest section. It was felt that this placed emphasis on the use of restrictive practices. Another respondent suggested that this section be amended to better fit with the Mental Health Commission's S69 rules.

One submission stated that the section on psychotropic medication as restraint should be removed as it is superfluous in light of medicinal products legislation and existing best practice guidelines in the prescription, administration and monitoring of all forms of medication for those professions who are professionally regulated and registered.

Two submissions called for the removal of figures 1, 2 and 3.

One respondent queried where the person's wishes, dreams, aspirations and preferences come in in the code.

## 5. Have you any **other comments** you wish to make on the draft code?

Several submissions felt it would be useful to make reference to the **HIQA draft national standards** for residential services for people with disabilities and to possibly integrate these into guidelines (4). It was suggested that it would be helpful if HIQA explicitly cross-referenced the code in their standards documentation. It would also be helpful if there was some signposting on how the remit of the MHC and HIQA might intersect and co-ordinate.

A key concern expressed in one submission related to the number of **untrained staff** working in intellectual disability services, particularly in community services.

One respondent called for more guidance on **rapid admission, emergency treatment, care pathways** for access to specialist services, treatment and discharge back to non approved residential and community settings within a professional and statutory framework. Liaison between the key worker, the MDT, interprofessional assessment and review, criteria for transfer back to primary service provider, training requirements of mental health staff in ID and ID staff in mental health issues were all highlighted in this submission.

It was noted that there is no specific mention in the guidance of those with autism, dementia, growing old with ID and complex physical and mental health issues (1) or mention of the use of restrictive interventions for people with autism (1).

No reference is made in the draft code to the predominance of drug treatments and limited opportunities for psychotherapeutic approaches such as counselling and psychotherapy (2). Diagnostic overshadowing is not mentioned.

It was felt that the draft neglected to advocate for the necessity of the physical resources required as laid down in A Vision for Change.



In the appendix, reference should be made to “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being...” (WHO constitution).

### **3.3 Other Comments unrelated to the draft code of practice**

It was suggested by one respondent that undergraduates should be offered opportunities to benefit from contact with staff and the population with intellectual disability.

The protection of informed consent and legal procedures for involuntary treatment should be specifically recommended by the guidelines. If mental health workers are working in an uncertain legal and/or human rights context, they need guidance on which direction we are currently advocating in practice (1).

A point was raised in terms of research and that guidance should be provided to those providing services to people with ID in terms of proposed research projects involving this population. In particular, the areas of epidemiological research; treatment, prevention and promotion outcome research; policy and service research; and research on the economics of MHS were highlighted (1).



# Appendix

## Appendix 1            Consultation Pack

17<sup>th</sup> September 2008

Dear XX,

One of the functions of the Mental Health Commission, as stated in Section 33(3)(e) of the Mental Health Act 2001, is to “*prepare and review periodically, after consultation with such bodies as it considers appropriate, a code or codes of practice for the guidance of persons working in the mental health services*”. The Commission has recently developed a Draft Code of Practice on Guidance for Persons working in Mental Health Services with People with Intellectual Disabilities in line with Section 33 of the Act.

The Commission is interested in obtaining the views of all those who have an interest in the draft code of practice. The document is currently in draft form and the final document will be published after the consultation process is complete and the views of those involved in the consultation have been considered by the Commission. We are asking that the views of all those who are interested in taking part in the consultation are returned to us by **7<sup>th</sup> November 2008**.

We welcome all methods of consultation e.g. focus groups, workshops, interviews, written submissions. Organisations consulting with service users, carers or advocates may wish to use the method of consultation which they feel is most appropriate for their members. To help facilitate the consultation process, we are providing a “*Consultation Summary Guide*” along with the full draft code of practice. The 10 page summary guide contains a summary of the draft code of practice and 4 specific consultation questions.

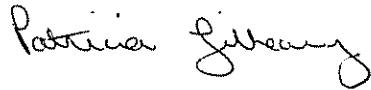
We would ask that the following information is provided with any feedback or submissions returned to us:

- a) **Method** of consultation used, and
- b) **Number** of people whom the feedback represents.

The Commission will consider all feedback received by the closing date. It is intended that the final code of practice will be published in early 2009. If you have any questions on this consultation, please do not hesitate to contact Ms. Lisa O' Farrell, Policy Officer in the Mental Health Commission on (01) 6362400 or at [lisa.ofarrell@mhrl.ie](mailto:lisa.ofarrell@mhrl.ie)

Thank you in advance for your involvement in this process. We look forward to receiving your feedback.

Yours sincerely,



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Ms. Patricia Gilheaney  
Director Standards & Quality Assurance



**Draft Code of Practice:**

**Guidance for Persons working in Mental Health  
Services with People with Intellectual Disabilities**

***Consultation Summary Guide***

**September 2008**

## Introduction

The Mental Health Commission has developed draft guidance for persons working in mental health services with people with intellectual disabilities. The draft guidance focuses on first principles and provides detailed guidance on issues identified by staff and service providers as requiring advice. The document is currently in draft form only. The final document will be published only after the consultation process is complete and the views of those involved in the consultation have been considered by the Commission. We, in the Commission feel it is very important to hear the views of relevant stakeholders, including staff working in mental health services, people using the services, families/carers and advocates, service providers and statutory and voluntary organisations, and for these views to be reflected in the development of the final code of practice. As a result, we are making this call for participation in the consultation process. We are also providing this information on our website for those wishing to return written submissions directly to us.

The draft code of practice has been put together by a multi-disciplinary working group (See Appendix of draft code for list of members). It has been informed by good practice guidance in Ireland and other countries such as Scotland and England. The literature, members of the working group and feedback from health professionals working with people with mental illness and intellectual disabilities identified several issues for which it was felt guidance was needed. These issues related mainly to person-centred planning, capacity and decision-making, and the use of restrictive practices. In particular, the absence of capacity legislation was highlighted as a major concern and the pressing need for such legislation to clarify the process of decision-making for adults who lack capacity. Of equal concern was also the increased risk of people with mental illness and intellectual disabilities being subjected to restrictive practices. We would like you bear in mind that in developing the draft guidance, the working group realised that the guidance could not cover every issue. As a result, the group decided to focus on the issues which they thought were of most importance and that services and staff would benefit most from having guidance on.

To help assist the consultation process, we have produced this “*Consultation Summary Guide*”. It is divided into 2 sections. Section A is a summary of the draft code of practice. It includes an executive summary, some key terms used in the draft code and the main points that are in the draft document. Section A is provided as an alternative to reading the full draft document.

Section B contains several questions that we would like those providing feedback to consider. All of these questions can be answered or only the ones that are of relevance to those providing feedback.

## **Section A – Summary of Draft Code of Practice**

### **Executive Summary**

The draft code of practice is divided into 5 sections. The first section provides an overview of why the guidance is needed, for whom it is intended and the context to the guidance. A key feature of this section is the four guiding principles. These principles are the cornerstone upon which the rest of the guidance follows. Part 2 addresses governance and the important elements of governance in helping service providers to implement the guidance. Part 3 provides guidance on a person-centred approach to care and treatment. The key areas of individual care and treatment planning, communication issues and considering environmental factors when delivering care and treatment to people with mental illness and intellectual disabilities are included in this section. Part 4 talks about decision making and capacity and emphasis is placed on capacity rather than lack of capacity. The final part, Part 5, provides guidance on the use of restrictive practices. Central to this section is that staff undertake a full consideration of whether restrictive practices are necessary in a situation where a person presents with problem behaviours.

### **Key Terms**

#### **Approved Centre**

A “centre” means a hospital or other in-patient facility for the care and treatment of persons suffering from mental illness or mental disorder. An “approved centre” is a centre that is registered pursuant to the Mental Health Act 2001. The Mental Health Commission establishes and maintains the register of approved centres pursuant to the Act.

#### **Capacity**

Capacity means the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made. Where a decision requires the act of a third party in order to be implemented, a person is to be treated as not having capacity if he or she is unable to communicate by any means. Any question as to whether a person has capacity shall be decided on the balance of probabilities (Law Reform Commission, 2006). It is important to note that there is no legislative definition of capacity.

#### **Individual care and treatment plan**

A documented set of goals collaboratively developed by the service user and the multi-disciplinary team. The care plan sets the direction for treatment and support, identifies

necessary resources and specifies outcomes for the service user. The care plan is recorded in the one set of documentation.

### **Intellectual disability**

The World Health Organisation (I.C.D.-10) and the American Psychiatric Association's (D.S.M-IV) diagnostic criteria for an intellectual disability outlines 3 core criteria a person must present with:

- A significant impairment of intellectual functioning
- A significant impairment of adaptive/social functioning
- Onset before adulthood.

### **Mental health service**

A service which provides care and treatment to persons suffering from a mental illness or a mental disorder under the clinical direction of a consultant psychiatrist (Mental Health Act 2001, Section 2).

### **Mental illness**

A state of mind of a person which affects the person's thinking, perceiving, emotion or judgment and which seriously impairs the mental function of the person to the extent that he or she requires care or medical treatment in his or her own interest or in the interest of other persons (Mental Health Act 2001, Section 3).

### **Person-centred service**

A person centred service is one which is provided, organised and designed around what is important to the service user from his or her perspective (National Disability Authority, 2005).

### **Problem behaviours**

Problem behaviours indicate behaviour that is of such frequency, severity or chronicity, as to require clinical assessment and special interventions/support. The behaviour is not a direct consequence of a psychiatric or medical disorder, and presents significant risks to the health and safety of the person and /or others, or has a significant negative impact on the person's quality of life or the quality of life of others. Examples of problem behaviours include verbal aggression, physical aggression to self (self-injurious behaviour), others or property (adapted from Diagnostic Criteria-Learning Disability, Royal College of Psychiatrists, 2001).

### **Restrictive practices**

Restrictive practices refer to the use of mechanical restraint, physical restraint, psychotropic medication as restraint and seclusion.



# Main Points

## Part 1 – Introduction

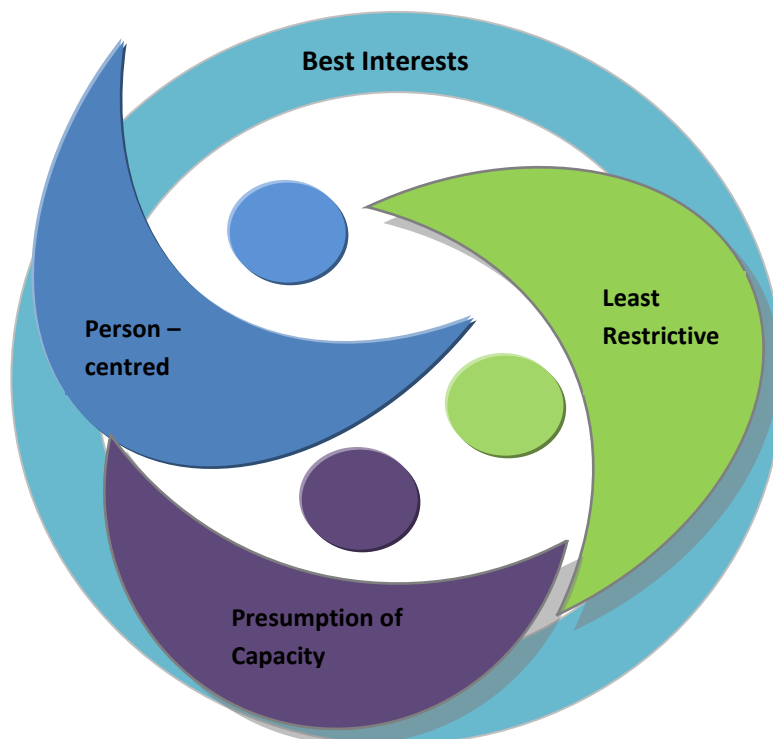
### Sections 1 – 4

This document is intended mainly for persons working in mental health services, but it is also relevant to service providers, managers of services, people using services, their families, carers, advocates and policymakers.

### Guiding Principles

The four guiding principles are:

1. Best interests
2. Person-centred approach
3. Presumption of Capacity
4. Least restrictive intervention



## Part 2 – Enabling Good Practice through effective Governance

Appropriate governance structures should be put in place to enable implementation of this principles and good practice guidance document. The areas that are considered important as part of good governance are given below.

### Sections 5 – 7

1. Service providers should ensure that **policies** are put in place on person-centred care and treatment planning, and on the use of restrictive practices. Restrictive practices should only be used in the context of a comprehensive policy on the management of problem behaviours.
2. **Education and training** should be provided to support the principles and guidance in the code. This should include education and training on person-centred approaches to care and treatment; training that focusses on both prevention and reactive strategies which may reduce incidents of violent and dangerous behaviour; and education and training on the use of restrictive practices. Services should have a policy for training staff.
3. It is important that services have a procedure for **communication and collaboration** with relevant external agencies for people with intellectual disabilities.

## Part 3 – Person-Centred Approach to Care and Treatment

The needs of people with intellectual disabilities and mental illness need to be considered using a person-centred approach. A key part of such an approach is creating an awareness amongst those working with people with mental illness and intellectual disabilities of person-centred values.

### Sections 8 – 10

1. Developing an **individual care and treatment plan** is one way of helping facilitate a person-centred approach. This plan should be multi-disciplinary in nature and should be evaluated with the service user and reviewed and revised as necessary. It should include a comprehensive assessment and the levels of support and treatment required to support the person's journey to recovery, in line with the person's assessed needs. A key worker should be identified to facilitate implementation of the plan and the person should have access to the plan.
2. **Communication issues** need to be considered, including the person's preferred way(s) of communicating, the best environment for that person for communicating, who best to give information to the person and encouraging involvement of family, carers and advocates to facilitate communication.

A communication passport is provided on page 18 of the draft code, as an example of a mechanism to support communication for those unable to communicate in a conventional way.

3. **Environmental considerations** need to be taken account of, such as the design and layout of environments. Providing the least restrictive environment to meet a person's needs is important and opportunities for engagement in meaningful activities should be considered.

## Part 4 – Decision making and Capacity to Consent

There is a **clear lack of mental capacity legislation** in Ireland making the issue of decision-making for those who may lack capacity a difficult one. This is one of the reasons why the Commission developed this good practice guidance.

### Section 11 – 12: Main Recommendations

1. The Commission believes that a person should be **presumed to have capacity** to make a decision for himself/herself unless it is proved otherwise.
2. People should be **assisted** to make their own decisions. Family and carers should be involved as advocates in this process and advocacy services should be made available.
3. A **functional approach** to capacity should be adopted meaning that capacity is assessed on an *'issue specific basis'*.
4. An **assessment of capacity** should be carried out, where necessary. An example of assessing capacity is provided on pages 23-24 of the draft code of practice.
5. A person should not be treated as unable to make decisions merely because he or she makes an **unwise or unconventional decision**.
6. Before a decision is made, consideration should always be given to the option **least restrictive** to the person's right and freedom of action.

## Part 5 – Restrictive Practices

The term “*restrictive practices*” is used in the draft code to refer to the use of mechanical restraint, physical restraint, psychotropic medication as restraint and seclusion. Part 5 is really only relevant to mental health services that are not approved centres. Approved centres have rules for the use of seclusion and mechanical restraint and a code of practice for the use of physical restraint, and these rules and code of practice have all been in place since November 2006. The section on psychotropic medication as restraint (Section 16) is relevant to all mental health services because no previous guidance from the Commission exists on this area.

### Section 13: Considering the Use of Restrictive Practices

1. Before restrictive practices are used, it should always be considered whether their use is necessary. Key to this is carrying out a **multi-disciplinary assessment** which looks at both the reasons within the person for problem behaviours as well as reasons outside the person.
2. Restrictive practices should only be used where a person poses an **immediate threat of serious harm to self or others** and they should only be used as a **last resort**.
3. The **least restrictive intervention** should be used, which is **proportionate to the risk** posed.
4. Restrictive practices should **never** be used due to **operational difficulties** in a service.

## Sections 14- 17: Using Restrictive Practices

The restrictive practices of mechanical restraint (Section 14), physical restraint (Section 15), medication as restraint (Section 16) and seclusion (Section 17) are considered in turn in the draft code. Below is an overview of the key recommendations made, which are common to all of these practices. There are a few more recommendations made on the use of psychotropic medication as restraint, which can be referred to on pages 32-33 of the draft code.

1. Restrictive practices should **not last longer than necessary** for their purpose.
2. The **service's policy** on restrictive practices should be followed.
3. The person should be **assessed / monitored** throughout the use of a restrictive practice.
4. The use of restrictive practices should be **clearly recorded** in the individual's clinical file.
5. The **multi-disciplinary team** should review patterns of use on an ongoing basis.
6. The person should be **informed** of the reasons for use of a restrictive practice and its likely duration. The multi-disciplinary team should **discuss** the use of a restrictive practice with the person after its use.
7. The person's **family, parent, carer or chosen advocate** should be informed, with the person's consent (except in the case of a child or where the person lacks capacity to consent in which case they should be informed anyway), of the use of restrictive practices.

An example of considering the use of mechanical restraint is provided on page 30 of the draft code, and an example of the use of psychotropic medication as restraint is given on pages 33-34.

## Section B – Consultation Questions

We welcome all comments on the content of the draft code. However, we are asking some specific questions which we feel will be helpful for us to hear about. It would be helpful to have your views on some or all of these questions, whichever questions matter to you. Any more specific points you want to make about the draft code are also welcome in question 5.

6. Do you think the **main areas** of importance for people with mental illness and intellectual disabilities receiving care and treatment in mental health services have been identified in the draft code? If not, what other key areas would you include?
  
7. Are you happy with the **guiding principles** of the draft code?
  
8. Are there points in the draft code that you think should be **changed**? If so, what changes would you make?
  
9. Are there points in the draft code that you think should be **left out completely**? Please identify these points and give a reason for your answer.
  
10. Have you any **other comments** you wish to make on the draft code?

Please return feedback to your organisation for submission to the Commission, or return directly to the Commission by the **7th November 2008** at the address below.

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## **Appendix 2 List of Stakeholders informed of the Consultation**

Clinical Directors of Approved Centres

Directors of Nursing of Approved Centres

Department of Health and Children

Disability Federation of Ireland

Health Information and Quality Authority

Inclusion Ireland

Irish Human Rights Commission

National Federation of Voluntary Bodies

National Disability Authority

Professional Bodies

Staff Associations