

Comments on the HSE's draft National Consent Policy

28 June 2012

Mental Health Reform welcomes this opportunity to comment on the HSE's draft National Consent Policy. Our comments are confined to Part One – General Principles.

General comments

Mental Health Reform welcomes the HSE's initiative to provide an organisation-wide policy on consent that covers all health services. One of the potential benefits of having a unified, national health service in Ireland is consistency in practice across geographical locations and care groups. Mental Health Reform therefore supports the scope of the draft policy articulated in Section 1.1, which covers "all interventions on service users in all locations".

The HSE's consent policy is being developed in the context of the Government's mental health policy *A Vision for Change* as well as recent developments in human rights standards to which the Government is committed. The principle of 'partnership' set out in *A Vision for Change* specifies that "service users and carers should be involved in a meaningful way with the planning and delivery of their care." The process of obtaining consent must be situated within a context of this kind of meaningful partnership between service users and service providers. Recovery-orientated mental health services also must provide meaningful choices for users of services. Thus consent must happen within a context where the individual has meaningful choices to consent to.

At a one-to-one level, working with service users as equal partners in their own care is essential to re-balancing the traditional power imbalance between service users and professionals in the mental health services. Service users often know from their own experience what works best for them in maintaining their mental health and what is ineffective. They know their experience of side effects from medications. They often know what triggers their mental distress. They know how they will define their own recovery.

Furthermore, participation is a core component of an approach based on human rights and is underpinned in the preamble of the Convention on the Rights of Persons with Disabilities. Participation by individuals in decisions affecting them is a crucial element of the right to health. Ireland has ratified the International Covenant on Economic, Social and Cultural Rights which recognises the right of all persons to the highest attainable standard of physical and mental health (Article 12).

It is vital, therefore that the process of obtaining consent reflects this partnership approach. Mental Health Reform welcomes the draft policy's articulation of a partnership approach under Section 1.3.

This draft consent policy also arises in the context of a review of the Mental Health Act 2001 being conducted by the Department of Health, as well as new capacity legislation that is expected to be published in 2012. The UN Special Rapporteur on health has noted that "persons with disabilities often suffer from [the] unjustified perception of being incompetent or dangerous to themselves or others. Such prejudices, coupled with existing laws and practices limiting legal capacity, often

compromise their informed consent." The expected capacity legislation is likely to substantially change the legal context within which consent to treatment is obtained.

In the mental health arena, according to Amnesty International Ireland, Ireland's Mental Health Act 2001 does not comply with international human rights law. The Interim Report of the Steering Group on the Review of the Mental Health Act 2001 acknowledges that the Act will need to be amended in order to embody a rights-based approach. In particular, the review group has recommended that the Act be revised so that the right to autonomy and self-determination is the key principle, as contrasted with the current pre-eminence given to the principle of 'best interests'. The review group also recommended that the consent to treatment provisions in the Act be revised, including provision that patients should be supported to make informed decisions regarding their care and treatment. The HSE's consent policy may therefore require revision on foot of any forthcoming amendments to the Mental Health Act 2001.

Recommendation: The consent policy should contain a commitment to its review on foot of any new capacity legislation and revisions to the Mental Health Act 2001.

Recommendations on specific sections:

Glossary: The glossary contains a definition of 'service user' that includes the recipient of health and social services, carers/family members/guardians, organisations and the wider public. This is at odds with the actual usage of the term throughout the document where 'service user' clearly refers to the individual in direct receipt of a health intervention only. The terminology for service user should be clarified so that it applies only to the person in direct receipt of a health intervention.

Section 1.5 Role of the Family: This guidance on the role of the family is welcome; however it is necessary to incorporate the limitations of the family role with reference to the right to privacy. The section should clarify that the circumstances where the family is included in such decision-making must occur within the context of the individual's right to privacy, as is specified in Section 1.6.

3.4 How and when information should be provided: This section should include people with poor mental health among those who may have difficulty making decisions. The recommended measures to assist in communicating information should also apply to people who may have difficulty making decisions due to poor mental health.

Section 4: Ensuring consent is voluntary: It is important to include a specific statement that threat of detention or involuntary treatment is not acceptable in order to obtain consent.

Report of the UN Special Rappoteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health: UN Doc A/64/272 (10 August 2009) para 69.

² See Amnesty International Ireland (2011) 'Submission to the Department of Health and Children on the need for a substantive review of the Mental Health Act 2001' available at www.amnesty.ie/mentalhealth

Section 5.2 Duty to maximise capacity: The identification of supported decision-making as important is welcome in this section, however the guidance needs to clearly state that providing such support is not optional, but essential.

The second paragraph in Section 5.2 should be amended to read "It is essential to give those who may have difficulty making decisions the time and support they need ...".

Section 5.4 When to consider incapacity: Mental Health Reform is concerned by the inclusion of 'misperception of reality' as a trigger for a capacity assessment. This statement runs the risk of creating a higher bar for a person with a disability than for a non-disabled person in determinations of capacity. Many people have beliefs that could be construed as out of step with reality and are allowed to live their lives without interference. Therefore this statement requires some limitation. The third criterion under Section 5.4 triggering an assessment of capacity should be limited to ensure that it does not provide too wide a scope for clinicians to question an individual's capacity to make a decision. Some limitation with regard to the risk of harm to the individual may be helpful.

Section 5.5 Assessing capacity to consent: The first sentence in this section should clarify that capacity is only assessed after all efforts to maximise capacity have been exhausted.

Section 5.6 should make reference to the Mental Health Act provisions on when a clinician can make decisions about mental health treatment without consent.

Section 6.3 When information would be harmful to the service user: Withholding information from a mental health service user runs the risk of undermining the partnership principle in *A Vision for Change* and therefore should be considered very carefully. It is particularly important that clinicians not be encouraged to use this rationale to withhold information on the risks or side-effects of treatments.

Therefore, Section 6.3 should include an explicit statement emphasising individuals' right to know the risks and side-effects of treatments.

About Mental Health Reform

Mental Health Reform is the national coalition of organisations working to improve mental health services and achieve implementation of the Government's mental health policy *A Vision for Change* in Ireland. Mental Health Reform works with its members through education, campaigning and support to help bring about structural and cultural changes in mental health services.

Mental Health Reform is available to discuss the above recommendations and answer any questions that would assist the HSE. Please contact Shari McDaid, Policy Officer at 01 612 1422 or via e-mail at smcdaid@mentalhealthreform.ie.