

National Consent Policy – Submission from the Citizens Information Board (June 2012)

Introduction

The Citizens Information Board (CIB) welcomes the publication by the National Consent Advisory Group of the draft National Consent Policy. The implementation of such a policy will make a significant contribution to ensuring that vulnerable groups in society are better protected both from a human rights perspective and from a perspective of having timely access to appropriate quality care in a manner of their choosing. The CIB has direct experience of the difficulties around consent and decision-making faced by people with impaired capacity from its involvement in delivering the National Advocacy Service (NAS)¹. NAS's concerns in respect of consent relate generally to decisions about day-to day or life circumstances in social care/residential settings rather than medical issues.

There are particular challenges around ensuring that consent by vulnerable adults, especially those with reduced capacity, is based on criteria that are fully transparent and fully respectful of individuals. This is particularly important in situations involving the provision of care or health interventions whether in the community, in hospitals or in residential care settings. It is also central to decisions around any removal of liberty.

Draft National Consent Policy Document

While the draft policy document is comprehensive and includes both social as well as health care interventions, there appears to be a stronger emphasis throughout on medical interventions. The term 'service user' used in the Draft National Consent Policy document masks the heterogeneity and diversity of the adult population being referred to and in that sense fails to deal with the complexity of the issue. People with different conditions may have very different needs around communication and decision-making, e.g., people with intellectual disabilities, people who are victims of a stroke or brain tumour, people with an acquired brain injury, people with motor neurone disease, people with multiple sclerosis, people with Alzheimer's disease, people with hearing impairment. The document may not give due cognisance to the significant differential between the status positions of many citizens/service users and that of medical professionals – in practice many people may 'defer' to medical expert opinion or feel unable to express a contrary opinion. As a result, their ability to give or withdraw consent may be compromised.

¹ The National Advocacy Service provides independent, representative advocacy for vulnerable people with disabilities. It is a countrywide service managed by five Citizens Information Services in Dublin (Clondalkin), Westmeath, Offaly, Waterford and Leitrim. The service is funded and supported by the Citizens Information Board.

The draft policy document does not deal adequately with situations where a person with limited or reduced capacity appears to be making a decision (consent or refusal) but on peripheral rather than central concerns, e.g., someone refusing an operation because they are afraid of needles; or someone who appears to want to leave a nursing home, although there is nowhere for them to go and they might be in danger if they left.

The definition of 'consent' on page 13 is somewhat limited and does not give sufficient cognisance to its underlying essence, viz. whether or not a person agrees to an action or series of actions. There should be a *Checklist* referring to the process of communication which sets out the steps to be taken prior to the actual consent to ensure that the decision is made voluntarily and in an informed way as the latter part of the definition states.

The term 'best interests' needs to be defined with particular reference to limited situations where 'best interest' considerations are deemed to override a person's preferences. The inclusion of the provision (p.24) that in certain situations, the treatment provided should be the least restrictive of the service user's future choices is a useful addition.

Key Considerations

The Role of Independent Advocates

The CIB is of the view that the National Consent Policy should have provision for people having access to an independent personal advocacy service. This would be consistent with the provision for the establishment of a Personal Advocacy Service in the Disability Act 2005 and the Citizens Information Act 2007. The role of the independent advocate would be particularly important in helping people make informed choices about their treatment or care and mediating between, the divergent views of individuals, healthcare professionals and relatives where these exist. The National Quality Standards for Services for People with Disabilities includes provision for access to an advocate as a criterion underpinning informed decision making and consent.

Supported Decision-Making

In its submission on the Scheme of Mental Capacity Bill, the CIB referred to the vacuum created by the absence of capacity legislation which highlights difficulties encountered in day to day decisions. The statement in the document, that "even in the presence of incapacity, the expressed view of the service user carries great weight" (p.25), is a very important one. On this basis and pending the enactment of the proposed mental capacity legislation, there should be more reference to and discussion in the National Consent Policy on the use of supported decision making where a person has reduced or limited capacity, where it should be used and when provision for substitute decision making may be required. In many instances, support from an appropriately trained person can enable a person to work through even a complex decision making process rather than have someone else give the consent or make the decision on his/her behalf. This is particularly relevant in the case of consent to treatment where there is uncertainty about a person's capacity to consent. Since capacity to consent can fluctuate and is frequently

circumstance-related, any over-riding of a person's wishes should have inbuilt safeguards and clearly defined limits provided for in the policy.

There should be provision for an appeals process for a person who wishes to challenge an assessment of incapacity – this is particularly important for people whose incapacity is related to mental health difficulties. There is no consideration in the draft document of the review procedures that need to be in place if a decision which is contrary to the person's stated preferences is taken. Where a person cannot consent to treatment, a doctor must go on record as taking responsibility for the treatment given. Feedback from NAS suggests that in some care centres it can be quite unclear as to who is the final decision-maker for a person who lacks capacity. This needs to be remedied with clearly set out protocols and procedures based on best practice models.

Participatory and Autonomous Decision-making

The issue of consent should be located within the broader framework of participatory and autonomous decision making, especially where these decisions have an impact on how the health, accommodation and support needs of the individual are met. Persons in receipt of health or social care services should be able to express their views on the services they receive and have these views taken into account in respect of the type of services provided and how they are delivered. The concept of autonomy is an important one for all vulnerable people. Autonomy means being free from coercion, and being able to determine one's own life course, even when frail or dying. There is a crucial distinction between 'decisional autonomy' and the 'autonomy of execution' in that the former is the capacity to have personal choices and values and make decisions, irrespective of an ability to execute those decisions independently. There is a danger that some people may be seen as non-autonomous, even though they are still decisionally autonomous. The question of how autonomous decision-making and related consent is to be protected in health and social care settings requires further consideration in the National Consent Policy Document. For example, there is a need for clearer guidance for health and social care staff in how best to include relatives in decision-making and there is a need to include additional and more specific criteria about how healthcare professionals can engage with families in ensuring that the preferences of their relatives are fully respected.

Presumption of Legal Capacity

The presumption of legal capacity means that everyone has legal capacity but some people need more support than others in exercising that capacity. In this sense, capacity should be assessed in a way which is fair and appropriate and which is free from prejudices based on external factors such as old age, mental illness or intellectual disability. The proposed Mental Capacity Bill stipulates that a person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success. It is important, therefore, that the National Consent Policy provides guidance and a checklist as to what are the practical steps to be taken in hospital, community care and long-term residential settings to implement this presumption of legal capacity. In particular, there is a need for more clarity as

to the respective roles of the hospital clinician and relatives in cases where there is a question about legal capacity.

Enhancing Access to Information

The CIB has consistently highlighted the important role information plays in supporting people at all stages of the life-cycle. The role of information is highlighted in the draft policy document. However, citizens sometimes need additional assistance with accessing and interpreting information and, as already stated, be given the option of having access to an independent advocate. The role of the advocate operates along a continuum from the provision of information on rights, options and choices, to providing support and assistance to people in asserting their rights and in making decisions. While health care professionals generally see themselves as acting as advocates for their patients, there may be an information deficit in that the healthcare professionals may not always share their 'expert' knowledge. It is also the case that there is a gap between those who are computer literate and proactive in their search for information and those who are not – the latter group are not well provided for under current arrangements.

Advance Care Directives

The principle of taking account of the person's past and present wishes is noted in the National Consent Policy document. There is no legislative provision at present for advance directives whereby a capable person could give binding instructions concerning situations (e.g. advance refusal of certain treatments) that may arise in the event of the person's incapacity. While this is a complex area, it is one which has a potentially significant role in ensuring that people whose capacity becomes impaired can have their wishes met which, for example, could be particularly important in an end-of-life care scenario. The issues identified in the Law Reform Commission's *Report on Bioethics: Advance Care Directives* are central to this debate and require fuller consideration, particularly the recommendation that a person should be entitled to refuse medical treatment for reasons that appear not to be rational or based on sound medical principles. There should be more discussion of, criteria identified and procedures set out as to how this issue is to be dealt with, particularly in end-of-life care settings.

People with Mental Health Difficulties and 'Voluntary' Detention

Feedback from NAS suggests that in some instances voluntary patients only remain as voluntary patients because they feel they have no choice in that they may feel that they will be detained involuntarily ('sectioned') if they don't comply. People can only be regarded as being voluntary patients if they have all the relevant information, have the capacity to make the decision and have genuinely consented to their admission. An area that causes concern for NAS advocates is people with intellectual disability/autism who are detained against their will (sometimes for their own safety) without the safeguards of the Mental Health Act, or any other overseeing legislation.

Coherence with Other Measures

All provisions included in the National Consent Policy should be informed and guided by the provisions of the proposed mental capacity legislation and the provisions of the Mental Health Act. The Government's stated intention to expedite the formal implementation of the *National Quality Standards: Residential Settings for People with Disabilities* is also important. The introduction of a similar set of mandatory standards for community-based services requires urgent attention. In this regard, the concerns set out in the Law Reform Commission's *Consultation Paper on the Legal Aspects of Carers* which dealt with the regulation of home care for vulnerable adults should be taken into account. This identified the need for robust structures of regulation, governance and guidance to ensure that appropriate legal standards are in place for professional carers and that care is provided in a manner that promotes the well-being and independence of the service user. The provisions of the pending National Carers Strategy should also be taken into account in the National Consent Policy.