

Consultation on Deprivation of Liberty: Safeguard Proposals

A submission from the Citizens Information Board

Introduction

The Citizens Information Board welcomes the opportunity to respond to this consultation. CIB is the statutory agency responsible for supporting the provision of information, advice and advocacy on public and social services. The Board has a particular remit in the provision of advocacy to people with disabilities. In that context CIB funds and supports NAS - the National Advocacy Service for people with disabilities. NAS will also be making a submission in response to this consultation.

The proposed ratification by the Irish state of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) is a positive development in the protection of rights of citizens. Achieving legislative clarity on the issue of deprivation of liberty in residential facilities for older people and for people with disabilities is also to be welcomed.

In all cases, deprivation of liberty should occur in accordance with due process of law, and subject to regular review and lawful challenge. Notwithstanding this foundational principle, care is required to ensure that the legal structures and processes that are put in place do not become so cumbersome and bureaucratic that they detract from the quality of care provided to those who require safeguarding and protection. In this context, the opportunity to contribute to this consultation on the draft Heads of Bill on Part 13 of the Assisted Decision Making (Capacity) Act 2015 concerning the Deprivation of Liberty: Safeguard Proposals is timely.

Head One: Definitions

Questions on Head 1:

1.1 Do you have any views on the definitions currently included in this draft Head?

- It is noted that the meaning of ‘deprivation of liberty’ is captured in the definitions of ‘admission’ and ‘admission decision’ and also in more detail in Head 2. Nonetheless, it is considered that a specific stand-alone definition including the circumstances in which it occurs would add clarity and would provide clear guidance for decision-makers. It would be important that care is taken in constructing such a definition and ensuring that professionals and others are trained and educated in its use. A number of studies of professionals’ views about the English Capacity Act found widespread disagreement on how to identify deprivation of liberty (Cairns et

al., 2011; Cairns et al; Griffith (2013) and difficulties in providing adequate supporting documents for decision-making purposes (Lepping, 2012).

- The term ‘deprivation of liberty’ has been the subject of much criticism in the UK (Bartlett, 2014; BASW, 2015; Law Commission, 2015; Law Commission, 2017). In general, it is considered to have negative connotations and can cause confusion and upset for family members, as well as at times discouraging professionals from using the policy.
- The term ‘admission decision’ does not adequately describe all decisions which result in continuous supervision and control of a relevant person. For example, a relevant person may lose capacity and be subject to deprivation of liberty after they have been admitted to a particular facility or may have an advanced dementia or cognitive impairment and require constant supervision within the home environment. Consultation to establish a more appropriate and accurately descriptive terms for this significant decision-making process should be undertaken.

1.2 In particular, do you have any views as to the types of healthcare professionals that should be included within the definition of “other medical expert”?

- Under ECHR law, medical evidence is required to justify a decision to deprive a person of their liberty. However, it is recommended that other healthcare professionals with specialist assessment expertise are included within the definition of ‘other medical expert.’ In England and Wales other professionals, for example Approved Mental Health Professionals (AMHPS), are often authorised by their agencies to carry out such assessments and, alongside other professionals, carry out subsequent Best Interest Assessments (BIA). Most AMHPS are social workers, with much smaller numbers of nurses, occupational therapists and psychologists. In Scotland, and in the proposed capacity legislation in Northern Ireland, a range of professionals are also defined in the legislation. In the Irish context it would be important to establish the role, function and mix of such professionals and to develop and deliver appropriate education and training for the role.

1.3 Do you have any other views specific to Head 1

- A statutory definition of restraint practices should be created. It is recommended that this definition is then used across all statutory and regulatory documentation such as HIQA or HSE guidance. Such clarity and consistency will promote understanding and standardised implementation across all health and social care settings where decisions about deprivation of liberty is being considered.
- As the ‘person in charge’ is proposed to have significant responsibilities with regard to assessing the capacity of persons who may be admitted to the centre, and has to pay due regard to the needs and wishes of other residents in the centre, it is recommended that the ‘person in charge’ should be a ‘medical expert’ as outlined above in 1.2 or should have the ability to easily and regularly access such expertise.

Head 2:

2.1 Do you have any views specific to Head 2?

- In addition to the description of what constitutes deprivation of liberty, it would be important to be more directive about exclusion and inclusion factors such as those

outlined in a significant legal judgement in the UK, which is commonly referred to as the Cheshire West¹ case:

- Whether the person agrees or disagrees with the detention
- The purpose for the detention or
- The extent to which it enables the person to live what might be considered a relatively normal life.

Head 3:

3.1 Do you have any views specific to Head 3?

- It is right that people should be able to plan ahead with regard to their future healthcare and/or safeguarding needs.
- As outlined in the explanatory notes, a public awareness campaign encouraging the use of the decision support mechanisms of the Assisted Decision Making (Capacity) Act, including advance healthcare directives and enduring powers of attorney, is to be welcomed. However, notwithstanding the possible success of such a campaign, it is likely that very many people will not have planned ahead with regard to these issues, therefore necessitating a large number of admissions in urgent circumstances (Head 5).
- In preparing for these forms of supported decision making, it is important to recognise potential barriers that prevent desired outcomes (Dickson et al, 2013; Godfrey & Hackett, 2015). It is also critical that health and social care professionals receive appropriate training so that they can support and guide individuals to forward plan and to express and document their expressed wishes and preferences.
- It is also recommended that the differentiation between assisted decision making and co-decision making is defined more specifically. In practice, the differentiation between “support” and “co-decision making” may not be clearly understood by relatives and friends of persons who may require assistance or wish to partake in equal (co-decision-making).

Head 4:

4.1 Do you think the term “under continuous supervision and control” should be defined? If so, what should this definition include?

- The term “under continuous supervision and control” derives from the Cheshire West case. However, the term should have a clear definition in the Irish context, given the different configurations of health and social care, and should also be accompanied by illustrative examples of what does and does not constitute continuous supervision and control in different settings. For example, the definition may vary considerably in hospitals, intensive care units, palliative care settings, nursing homes for elderly people, centres for people with varying degrees of intellectual disability and capacity.

4.2 When the person in charge has reason to believe that a relevant person may lack capacity to decide to live in a relevant facility, who should be notified with a view to affording them the opportunity to make an application to Court under Part 5 of the Act? This issue also arises in Heads 3(3), 7(4) and 8(1).

¹ P v Cheshire West and Chester; P and Q v Surrey County Council [2014] UKSC 19.

- This places a burden of responsibility on persons in charge of facilities. Clear guidelines and/or specialist training are required for persons in charge to enable them to make competent assessments of the capacity of persons who use their facility or who are to be admitted to their facility.
- In many cases, assessments of capacity may form part of the ongoing care plan for existing residents. Identification and appointment of co-decision makers, decision-making representatives or attorneys may be part of the care-planning process.
- The current situation where general social workers, Adult Safeguarding social workers and independent advocates do not have authority to enter private nursing homes or to offer support and assistance to individuals living in private residential care facilities should be reviewed in consideration of their potential advocacy role for individuals in residential/nursing home care.

4.3 Do you have any other views specific to Head 4?

Head 5

5.1 In subhead (1), what are your views on the proposed circumstances in which an urgent admission can be made?

- Where there are no alternatives, the proposed circumstances outlined in subhead 1.5 warrant urgent admission of a relevant person.
- It is possible that such circumstances will arise frequently in cases of a sudden deterioration of a person's capacity, a sudden increase in their care needs or a sudden breakdown of their formal or informal care arrangements and where no advance care provisions are in place.
- While it is acknowledged that medical evidence should be sought without delay, the timescale of three days may not always be practical, particularly at holiday weekends and where out-of-hours services are not properly resourced.

5.2 In subhead 2(b), should a health professional other than a registered medical practitioner be able to provide medical evidence? If so, what type of healthcare professional? This issue also arises in Head 6(2).

- As noted in section 1.2 above, it is recommended that other healthcare professionals with specialist assessment expertise are included within the definition of the 'other medical expert' and therefore could be able to provide medical evidence in these circumstances.

5.3 In subhead (7), who should make the application to Court if no one else does so? Do you have a view on the proposed role of the Director of the Decision Support Service? This issue also arises in Heads 7(6), 7(11) and 8(3).

- The appointment of the Director of the Decision Support Service in October 2017 is welcomed. This role falls within the remit of this service, though the ability to make the application to court within the defined time-frame will depend on the resources available to the Director and also on the number of available and suitably qualified people that have been appointed to the panel of Decision-Making representatives.

5.4 Do you have any other views specific to Head 5?

Head 6:

6.1 Is the evidence of one medical expert sufficient?

- Independence and objectivity is essential when making important decisions about a person's liberty. This is particularly the case where the same health and social care professionals who are responsible for depriving a person of their liberty are also engaged in delivering ongoing care to that person.
- The availability of independent medical experts who will not have already known the relevant person is a crucial safeguard. However, this requirement could pose significant challenges in the Irish system which is currently short staffed and under significant pressure. In December 2017, the HSE National Director for Mental Health Services reported significant difficulties in recruiting and retaining staff and outlined that staffing levels were at 80% of recommended delivery levels and in some areas, such as Old Age Psychiatry, were as low as 61% (O'Connor, 2017).
- In situations where the person objects to the proposed care arrangements, evidence from another medical expert could help to resolve the dispute.

6.2 Do you have any other views specific to Head 6?

- The requirement in Head 3 (a) and (b) that admission decisions should be made where it is necessary to protect the relevant person and/or where there is no other appropriate and less intrusive manner of protecting the person from harm raises complex questions and concerns. For example, the UK Law Reform Commission (2017, p13) cites confusion over the role of best interests assessments and states that families informed them that: "*placement decisions were often dressed up as being in the persons best interests when really they were being taken on the basis of the cheapest available option*" or that "*people were offered no choice over their placements thus leaving no room for a 'real' best interests decision.*" It may be advisable therefore that a strong well-being principle is followed rather than the principle of best interests. The Assisted Decision Making (Capacity) Act strongly favours the approach of decisions being made based on the will and preference of the person affected over best interests.
- The lack of choice and availability of placement and support options, especially home support options, in Ireland are a concern in this regard. For example, older people are regularly obliged to go into long-term care prematurely and unnecessarily because of the lack of service availability. This issue is particularly prevalent for people with a mild/moderate dementia (Donnelly et al.2016). For many people, the reason that they require admission to a care setting - where a deprivation of liberty will occur - is that it is not considered safe for them to be unsupervised in their home setting. However, if a tailored range of in-home supports were available then the question of their admission to a care setting would not arise or would arise in fewer situations. Therefore, it is recommended that priority is given to expanding the availability of flexible in-home supports to facilitate people to stay in their own homes for longer and that a statutory right to home care should be established, similar to the statutory right to nursing home care under the Nursing Home Support Scheme Act, 2009.²

Questions on Head 7:

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http://www.citizensinformationboard.ie/downloads/social_policy/submissions2017/Home_Care_Services_CIB_Submission.pdf

7.1 In subhead (2), do you have views on how the issue of fluctuating capacity should be addressed?

- The issue of fluctuating capacity should be specifically addressed in the legislation in line with the general principles of the Assisted Decision Making (Capacity) Act, which recognises that capacity can fluctuate in certain cases. To not do so would result in a continuous cycle of assessment, court applications and re-admission and could expose health and social care professionals to legal risks.
- It is considered that the view of the UK Law Commission (2017, pp12-13) on this point is applicable to the Irish context: *“A risk of harm may be continuously present in cases of fluctuating capacity owing to the risk of a person losing the ability to keep themselves safe whilst at large on their own”* and therefore *“it is legitimate to authorise arrangements that remain in place even during limited periods of capacity to consent or object to the arrangements.”*

7.2 In subhead (2), do you have a view on the length of time that would be considered a “short period”? This issue also arises in Heads 7(8), 7(12) and 8(5)

- It is considered that the issue of fluctuating capacity should be addressed as part of an individualised care plan for the person and in this context a ‘short period’ should be defined specifically with regard to the individual’s care needs and history of care needs. Fluctuation in capacity for one individual may last minutes, but for others it might last for hours or days.
- It should be acknowledged however that on the occasions where individuals regain their capacity to consent or their capacity to object to care provisions, this may cause distress or upset for the individual concerned and indeed for staff or family members who must explain the rationale for the imposition of such arrangements. It is recommended that constructive management of such instances should also be addressed as part of the individual’s care plan and in a manner that minimises distress or upset for the individual concerned.

7.3 Do you have any other views specific to Head 7?

- Notwithstanding the points outlined above in 7.1 and 7.2 with regard to fluctuating capacity, it is important to recognise that situations may arise where a person who previously lacked capacity may regain it permanently or for longer than a ‘short period.’ It is recommended that court applications for review should be treated expeditiously.

Head 8:

8.1 Do you have any views specific to Head 8?

- The transitional arrangements for existing residents on commencement of this legislation are a matter of concern in terms of the resources required to ensure compliance with the law.
- Census figures from 2016 show that over 22,700 people were resident in nursing homes. Figures from 2012 indicate that at that time there were over 8,000 people with disabilities in residential care. Not all of these people lack capacity to consent or are subject to deprivation of their liberty, but all will need to be assessed and it is

highly probable that many are experiencing a deprivation of their liberty to which they lack capacity to consent. Implementation of the law in this regard will require significant resources, both in terms of assessment and in terms of court applications. It will be important to ensure that care for this vulnerable grouping is not compromised through this process.

Head 9:

9.1 Do you have any views specific to Head 9?

- All restrictions or deprivations imposed on a person should be subject to frequent review and, where appropriate or necessary, subject to appeal or challenge.
- It is considered that in this context the deprivation of liberty and the admission decision are inextricably linked and therefore 'hooking' the deprivation of liberty review to the review of capacity is reasonable.
- It may be that there is a case for extending the period of judicial review in situations where there is a long-term and stable diagnosis which results in a lack of capacity.

Head 10:

10.1 Do you have any views specific to Head 10?

- Chemical restraint is degrading and inhuman. In order to comply with the ECHR, legislation should be enacted in Ireland to enforce an outright ban.
- Medication should only be administered for a medically identifiable condition and, in this regard, clear and comprehensive records should be maintained.
- The appropriate use of drugs to reduce symptoms of medical conditions such as anxiety, depression or psychosis does not constitute restraint. However, a fundamental principle is that informed consent should be sought before any intervention is commenced and before medication is prescribed.
- For the purposes of clarity, illustrative guidelines which clarify circumstances where administration of medication could be construed as chemical restraint should be drawn up. For example, healthcare staff should be clear that the use of sleeping pills or sedation for staff convenience or disciplinary purposes is not acceptable.
- In order to avoid duplication and to ensure clarity and consistency, policies with regard to the use of chemical restraint in exceptional circumstances should replicate those of other regulatory bodies such as HIQA and the HSE. For example, the HSE National Consent Policy (2017, p.29) recommends a functional or decision-specific approach to the assessment of capacity and also that capacity should be judged on an issue-specific and time-specific basis. Such an approach is compatible with the proposed heads as it recognises that capacity may fluctuate and that there is a hierarchy of complexity of decisions and that cognitive deficits are only relevant if they actually impact on decision making.
- In emergency situations where treatment is considered immediately necessary, the HSE National Consent Policy (2017, p.33) recommends that the treatment provided should be the least restrictive of the future choices of the person and that where possible, those close to the person should be consulted with as they may be able to provide insight into the person's preferences.
- It is recommended that requirements for medication and all healthcare interventions are reviewed regularly as part of the person's individual care plan. Such a review is well placed to assess the capacity and/or fluctuating capacity of the

person to make decisions with regard to their care. The individual care plan would also provide valuable insight to inform decisions in emergency situations.

Head 11:

11.1 Do you have a view on the types of records that must be kept under this Head?

- Deprivation of Liberty is a serious issue and clear records of the decision and the basis for the decision should be maintained and up to date.
- However, it is also important that the system does not become cumbersome or overly bureaucratic (Bartlett, 2014). Consideration should be given to incorporating such records into the individual care plan so that paperwork and duplication is minimised.

11.2 Do you have any other views specific to Head 11?

Head 12:

12.1 In subhead (1), do you think that the Minister should be empowered to make regulations on any other aspect of the Heads?

- It is considered that the Minister should be empowered to make regulations in this regard as this will facilitate a more responsive and flexible system.
- To avoid duplication and to streamline implementation, regulations with regard to these safeguards should replicate regulations that are in place elsewhere, for example, HIQA and HSE regulations.

12.2 In subhead (2), do you have a view on any other policy and procedure that should be included in this subhead?

- It is recommended that a detailed code of practice with clear definitions of all aspects of these safeguards is drawn up. The code of practice should contain illustrative examples and be easily understood and accessible for professionals, families and service users.

12.3 Do you have any other views specific to Head 12?

Head 13:

13.1 Do you have a view on the proposed offences set out in this Head?

- It is noted that Subhead 1 refers to 'deliberate' contravention of the safeguards in Heads 4,5,6 or 7. More clarity is required in order to prevent inadvertent contravention of the safeguards.

13.2 Do you have any other views specific to Head 13?

- Delays due to circumstances out of the control of a person making an admission particularly in the case of urgent admissions may result in inadvertent contravention of the safeguards and may cause anxiety or concern.

General Questions

14.1 A number of the Heads - 5(2)(b), 5(3), 5(4), 5(7), 5(8), 7(6), 7(9), 7(11), (8(1) and 8(3) - set down timeframes within which certain actions must be taken. Do you have a view on any of these proposed timeframes?

- As noted in the comments under section 5.1 above, specification of timescales may be problematic, particularly at holiday periods or in areas where out-of-hours services are not properly resourced. It may also be better in some situations to increase the timescale in order to access relevant details of the person's previous medical history which would support a more informed decision in the person's best interests.

14.2 The draft Heads apply to older people, persons with disabilities and people with a mental health illness. In terms of timeframes and in light of the existing provisions of the Mental Health Act 2001, should those with mental health illness be treated differently to others?

14.3 Do you have any other views on the draft provisions?

- When a citizen is being subject to deprivation of liberty safeguards, it is crucial that appropriate reciprocal measures are in place to protect rights. In the case of the English Mental Capacity Act, an Independent Mental Capacity Advocacy system was introduced to protect the needs and rights of relevant persons who appeared to have little or no social and familial support (Newbington et al, 2015). It is recommended that such an advocacy system should be resourced by the State. This system would work in tandem with the proposed Decision Making Support Service.

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