Submission as part of the Consultation on Deprivation of Liberty: Safeguard Proposals

Department of Health
1. Introduction

Sage is a support and advocacy service whose mission is to promote, protect and defend the rights, freedom and dignity of vulnerable adults and older people. It was established in 2014 with funding from the HSE and The Atlantic Philanthropies with support and governance provided by Third Age. Sage Advocacy clg assumed responsibility for governance of the service on 1st March 2018.

The development of Sage has been influenced by the scandals of Leas Cross and Aras Attracta. Through its dedicated support and advocacy service, Sage works to ensure the will and preferences of the person can be heard and implemented, independently of family, service providers or systems’ interest. The model to which Sage works is of core paid staff supported by, and in turn supporting, trained volunteers. Some of these volunteers act in support roles, some are advocates and some have specialist legal, financial or other professional skills.

It is conservatively estimated that the work of Sage in 2016 impacted on the lives and practice of some 20,000 people. We have worked with over 700 people where a diagnosis of dementia, capacity and cognition issues or mental health were amongst the initial presenting issues at the time of the referral. Sage works to uphold the right to self-determination and autonomy by supporting a functional approach to capacity and ensuring the person is enabled to make decisions that affect them.

Sage works with vulnerable adults and older people at transition points in the person’s life when they are adapting to a cognitive impairment, moving from home to residential care, in acute hospital, transitioning from hospital to residential care and when they are experiencing significant loss associated with these changes.

Sage welcomes the opportunity to make a submission as part of the Consultation on Deprivation of Liberty: Safeguard Proposals. In making this submission Sage is incorporating experience and evidence gathered by the service since it commenced supporting vulnerable adults in residential care/congregated settings, acute hospital settings and in the community in 2014.

Section 2 of this submission addresses General Views in relation to the Heads of Bill, this section raises overarching points regarding the draft Heads of Bill as requested in Section 14.3 of the Consultation Document.

Section 3 outlines the role of advocacy. Based on Sage experiences and related research Section 4 briefly sets out the risks of and experiences of deprivation of liberty, defacto deprivation of liberty due to a lack of suitable accommodation and care to meet individual’s needs, and the occurrence of chemical restraint. Section 5 addresses the specific provisions of the Heads of Bill following the format of the Consultation Document.

2. General Views: Section 14 of the Consultation Document

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

Human Rights Principles

- Legislation in relation to deprivation of liberty and related safeguards which will form Part 13 of the Assisted Decision-Making (Capacity) Act 2015 [ADM Act 2015] to prevent unlawful interference with the right to liberty should be focussed on human rights and adhere to human rights principles and standards, particularly as the right to liberty is a convention right under the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the European Convention on Human Rights (ECHR).

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1 The main Objective of Sage Advocacy clg is “To promote, protect and defend the rights and dignity of vulnerable adults and older people, the prevention of cruel, inhuman and degrading treatment and deprivation of liberty, and the enhancement of personal autonomy and decision making in all care settings and in the transition between them within the Republic of Ireland”.
Considering a human rights focus the title of Part 13 and associated provisions should be phrased in the context of safeguarding and protecting liberty. To note the Law Commission of England and Wales following an extensive consultation process have proposed ‘Liberty Protection Safeguards’ as the title for procedural arrangements to authorise a deprivation of liberty.

Safeguards to protect the right to liberty should be for the equal benefit of all people who may be detained and deprived of liberty in any setting, and should apply to, but not limited to, a person residing at home, in a community dwelling, in supported living accommodation, with a housing association, in acute hospital or in respite care.

Safeguards to protect the right to liberty should be for the equal benefit of all people who may be detained and deprived of liberty to ensure that the person has been fully informed, is made aware of all their options in a manner which is understandable to them and is making a decision to be in a place of residence where their liberty may be restricted. A person who is vulnerable and in need of care and treatment requires safeguards against coercion and undue influence. See Section 4 for further discussion on this.

The terminology used in the Heads of Bill, for example ‘admission decision’ and ‘routine admission’ do not respect the inherent dignity of the relevant person, particularly in the context that the outcome of the decision may result in a deprivation of the person’s liberty. As points of reference some of this terminology is used in this submission however it is not intended to endorse the use of it. This is further addressed in Section 5 below.

**Deprivation of Liberty**

- It has been noted in the context of a review of Deprivation of Liberty Safeguards in England and Wales that the question of the purpose of safeguards should be considered, and for human rights to be meaningful it should be looked at from the perspective of the person. Safeguards and related processes should be examined from the perspective of how the person will benefit, and how their rights and quality of life will be enhanced as they experience them. A person may be subject to care and treatment to the extent that care is intrusive, or they are completely dependent on the provision of care, and how care is provided to them creates a risk of deprivation of liberty.

- The developing concept and understanding of deprivation of liberty should be considered in developing legislative provisions. The Scottish Government’s proposals for reform of the Adult with Incapacity (Scotland) Act 2000 considers recent cases of the European Court of Human Rights and suggests

> ...that significant restrictions on liberty are as much about how a person lives as where the person lives and it is important to distinguish between decisions as to where a person lives and the conditions that should apply there:

  - If a regime looks like detention it does not lose that characteristic just because the person does not display opposition.
  - If a regime does not look like detention but the adult displays opposition to staying there, then that should be considered as placing significant restrictions on that adult’s liberty
  - A person may be perfectly content to agree to move to another place of residence but may not agree with aspects of their care there which amount to significant restrictions on their liberty.

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A person may remain in the same residential setting but become subject to changes in aspects of their care which in themselves mean they become subject to significant restrictions on their liberty.

Compliance with ADM (Capacity) Act 2015

- The current draft of the Heads of Bill and accompanying Explanatory Notes are not in line with the ADM Act 2015 which creates a statutory presumption of capacity and the processes outlined in the draft do not sufficiently require a process of capacity building with the person and supported decision-making in accordance with the ADM Act 2015 to enable the person to make their own decision. The current draft does not adequately reflect the requirement that a person’s capacity should be assessed functionally to determine if the person has the capacity to make the relevant decision.

Independent Advocacy

- The role of an advocate and right of access to an independent advocate should be provided for with the inclusion of an Independent Advocate in the ADM Act 2015 by amendment to Section 101. Where a relevant person cannot appoint an advocate, an advocate should be appointed for them, particularly in circumstances where a person does not have a co-decision-maker, decision-making representative or attorney for the relevant decision.

Care Needs

- The lack of a statutory right to homecare, lack of flexible models of care to meet individual’s needs, and lack of adequate homecare service provision risk undermining the State’s intentions and obligations to meaningfully implement a process of ensuring a person is not unlawfully deprived of their liberty. In order to have care needs met a person may be forced to reside in a residential care home, respite care centre or spend a prolonged period in an acute hospital against their expressed wishes, or their known will and preference, due to a lack of homecare or suitable alternatives to meet their needs.
- An assessment of the person’s care needs and interests to determine if the person would benefit from being resident in a ‘relevant facility’ is a separate process to the decision whether or not a person is to reside in a ‘relevant facility’. Both should be given appropriate consideration and assessment with the most appropriate healthcare professionals and in accordance with the principles of the ADM Act 2015. An assessment of the person’s needs and how these needs can be met should be fully explored in the context of all options, and this should be communicated to the person to enable the person to make their own decision about care and treatment. The decision that a relevant person’s care needs require that they will reside in a ‘relevant facility’ and a determination that they are deprived of their liberty by the conditions within the facility are two separate processes. The granting of an ‘admission decision’ without determining if the person is deprived of their liberty in the ‘relevant facility’ risks an order to deprive a person of their liberty when it is not necessary to do so.
- The Heads of Bill in the current draft imply that the decision to live in ‘relevant facility’ will be a permanent decision, it does not allow for this decision to be altered easily if a person’s capacity is regained, to facilitate a change of mind, a change to a different ‘relevant facility’, or where a person may move between places of residence and care. A person should be supported to give their consent to care, treatment and whether or not they will reside in a ‘relevant facility’, therefore all practical steps should be taken to build the capacity of the person and support the person to make their own decision through the supported decision-making structures under the ADM Act 2015, and to enable a person to create an Enduring Power of Attorney or Advance Health Care Directive where this is possible.
Other issues

- There is significant responsibility and authority placed on one individual, namely a person in charge of a ‘relevant facility’, or the healthcare professional on behalf of the person in charge, to take action and make determinations in relation to a person’s decision-making capacity without input from other parties. While individuals may act according to professional ethics, additional safeguards need to be in place to protect vulnerable adults in need of care and treatment from perverse incentives of privately operated businesses which have an interest in maintaining and generating profit.

- The provisions outlined in the Heads of Bill require applications to court for ‘admission decisions’, considering the likely demand on the court there is a risk of prolonged time periods where a person is arbitrarily deprived of their liberty without timely access to a legal process.

- To ensure a range of safeguards are in place for people who may experience restriction on their liberty in care settings, the Optional Protocol to the UN Convention against Torture (OPCAT) should be ratified, with the inclusion of residential care settings for older people and people with disabilities to be monitored by a National Preventative Mechanism.

3. The Role of Advocacy

The right to have your ‘voice’ heard and to participate in the making of decisions which affect you is a fundamental principle in a democratic society. It is about independence and interdependence. It is a principle simply stated as “Nothing about you / without you”.

The underlying principle of advocacy is to facilitate and support people in speaking for themselves and in articulating their own needs. In practice, advocacy often entails the use of a number of approaches working together with supports being provided at various points along a continuum.

Advocacy is underpinned by a core set of values and principles, and acts to empower people as well as safeguarding those who are vulnerable. A person’s autonomy as demonstrated by choice, control, decision-making and privacy is an indication of a person’s quality of life. Empowerment is enabling a person to be autonomous acknowledging a person’s right to be mistaken, to change their mind, to take risks and to make what may be perceived as ‘unwise’ decisions.

The Council of Europe Statement on the Rights of Older Persons states that older persons are entitled to lead their lives independently, in a self-determined and autonomous manner (Paragraph 9). Paragraphs 12 and 13 of the Recommendation provide:

*Older persons enjoy legal capacity on an equal basis with others.*

*Older people have the right to receive appropriate support in taking their decisions and exercising their legal capacity when they feel the need for it, including by appointing a trusted third party of their own choice to help with their decisions. This appointed third party should support the older person on his or her request and in conformity with his or her will and preferences.*

The UN Convention on the Rights of Persons with Disabilities sets out the right to enjoy legal capacity on an equal basis with others, and the right to make decisions and be actively involved in the decision-making process in all matters concerning the person.

The concept of independent advocacy is a centrally important one, i.e., assistance provided by an organisation that is structurally, financially and psychologically separate from the services that deliver health and social care as well as from people’s families. It is important to recognise that many of those who provide services to people see themselves as advocates for those they care for, although not formally

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4 Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons. (Adopted by the Committee of Ministers on 19 February 2014 at the 1192nd meeting of the Ministers’ Deputies).
designated as such. At the same time, it is also necessary to recognise that service providers may sometimes experience a conflict between advocacy and their primary role in an organisation and, for this reason, an independent advocacy service is usually seen as ‘the better option’.

While the role of families and relatives as advocates is crucially important, there is an additional and necessary perspective that independent support and advocacy can bring to ensure that the voice of the vulnerable person is clearly articulated in all circumstances, and, particularly, where crucial decisions are being made in relation to medical interventions, place of living and care arrangements.

Legislation relating to capacity and legislation relating to the safeguarding and protection in the jurisdictions of Scotland, and England and Wales recognise or give the right of access to an independent advocate. The Law Commission for England and Wales review of the Deprivation of Liberty Safeguards in place since 2009 reported that the provision of an advocate to represent and support the person is a safeguard, and “…that advocacy would be provided automatically and on an opt-out rather than an opt-in basis”.

The ADM Act 2015 recognises the concept of advocates as provided in Section 103(2)(x) and in the context of safeguarding, the ‘Adult Safeguarding Bill 2017’ introduced in April 2017 provides for the appointment of an independent advocate to represent and support the individual.

4. Issues of Concern

Deprivation of Liberty

- In Sage’s experience it is not uncommon for a third party, often a next of kin, to be asked to sign the contract for care to consent to care although they may have no legal authority to make decisions for that person. The third party is also consenting to provisions of the contract including to immediately terminate the contract without adequate safeguards. Social workers working with older people have reported that only 61% of people in a sample of cases were involved in decision-making about their care, with involvement being described as tokenistic in some cases. Similarly, only 55% of people with dementia were involved in decision-making about their care.

  “Health professional raised concerns as currently staff are stopping P2 from leaving [the] ward or hospital, mentioned ‘absconding’ and bringing P2 back to [the] ward despite having capacity”

1. From Sage Qualitative Analysis, Annual Report 2016

- Currently, in the absence of the commencement of the ADM Act 2015 there is neither a statutory obligation to use a functional approach to capacity to determine the person’s capacity to consent to residence in a care setting, nor a process to support and assist the person to make that decision. The

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9 Sage raises concern about the nature of some contracts for care seen by the organisation, which include provisions for termination of the contract by a ‘notice to quit’ and subsequent loss of a place to live, without sufficient safeguards for the person. Contracts for care can be terminated with immediate effect where a person is considered disruptive and/or aggressive or a person’s behaviour is a risk to health and safety of another person. A person making a complaint can be considered disruptive, or a person could be considered disruptive if the residential care centre does not staff with adequate skills to manage challenging behaviours related to dementia or other cognitive impairment. Recent data from Sage indicated that 27 of 63 cases relating to the topic ‘accommodation’ concerned a resident receiving a ‘notice to quit’ the residential care centre.
process of applying for the NHSS scheme, commonly completed by a person’s next of kin if a person is unable to complete it, does not give any other legal authority to make decisions on behalf of the person but in the absence of an Enduring Power of Attorney it is commonly misinterpreted as giving next of kin authority to decide the person will be admitted to residential care, which residential care setting they are admitted to, and making care related decisions for the person while in residential care.

- In Sage’s experience many residential care settings for vulnerable adults and older people are commonly secured by key code locks as a safety mechanism, requiring residents to ask permission to leave the premises. In Sage’s experience, the *de facto* detention can extend as far as limiting people’s access to recreational grounds outside of the building, justified by an assessment that the resident is a “fall risk” or likely to “escape”. While explanations for policies may point to efforts to introduce safety measures to protect some of the people in a residential care centre, the impact of such measures can be the *de facto* detention of all the people who reside within that centre.

Sage Experience 1:

Rosie agreed to enter residential care setting after a fall, she was in a nursing home under the NHSS. Rosie told of her experience on Newstalk Radio.

The nursing home was near her family, but far from where her own home and friends were. She became increasingly unhappy in the nursing home and told her family she wanted to go home, but they felt there was no one to look after her, Rosie felt she was quite capable of looking after herself. She recounted what happened when she tried to leave the residential care setting, when asked by the interviewer if she spoke to the nurses about going home she said….

“….I did, and they, they sided with my daughters “what do you want home for there’s nobody at home to look after you.” I said I don’t care I’m still going to go home. So I really didn’t know who to turn to and I was thinking and thinking and thinking to myself………..I had my case packed and I thought to myself well they all know I want to go home so I had my case packed, every single thing except, you know, when you’re there for a long time you accumulate a lot of stuff so I thought I’ll have to come back, I’ll have to get a taxi and I’ll have to come back for some of my stuff later. So I said that to one of the nurses, and she was quite abrupt and told me to get my stuff out of here now, “you can’t go without taking out your stuff, we need the room.” I had my case packed and I thought I have nothing to do now just to sign myself out. She said “no way you can’t go out of here unless one of your family signs you out.” And I said excuse me they don’t want me to go home, “we know that so you’ll have to get one of them to sign you out you can’t leave here anyway”. And they actually locked the doors and they would not let me out, I couldn’t do a thing……they kept telling me we’ll ring your family now and they’ll be here and they kept telling me that for about 8 hours. I had to go back and eat my humble pie and wait there again.”

During her attempt to leave the nursing home she was threatened with the police. Rosie eventually left the nursing home and travelled 250km by taxi to her home. She is now living in her own home with home help support, and is connected to her friends and neighbours.

Chemical Restraint

- The Department of Health’s policy on restraint in nursing homes aims “to restrict the use of all forms of restraint to those exceptional emergency situations where it is absolutely necessary. Where restraint is necessary it should only be applied in accordance with the law and best professional practice.”

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guidance on restraint for residential care centres states “(a)administering sedatives to a person who wanders during the night primarily for the convenience of staff is an example of chemical restraint which is not acceptable in any designated centre.”

The Irish Medical Council permits within their Guide to Professional Conduct and Ethics the use of “appropriate physical or chemical restraint where this is in the patient’s best interests” if the patient lacks capacity to make a decision about treatment or examination and there is a risk of harm to themselves or others. It has been recognised that there is often misunderstanding about the distinction between medication being used for therapeutic reasons and medication used to control behaviour amongst medical practitioners in residential care centres and in acute hospitals.

- In 2015, Sage wrote to the then Minister for State for Mental Health, Primary Care and Social Care and then Minister for Health to highlight Sage’s experience in practice as a support and advocacy service that “[f]or a variety of reasons, some based on a lack of skill in addressing behaviours which are challenging, some based on ignorance of basic human rights and some based on expediency, it would seem that a culture has developed in which the use of chemical restraint has become normalised i.e. it is being used as a first rather than a last resort”. Sage recommended the introduction of a legislative provision on the issue.

- As an advocacy service working with vulnerable adults Sage has observed the use of sedation to manage behaviours for the convenience of staff and benefit of other people in congregated settings and has highlighted to a hospital administration the use of sedation in response to a patient’s refusal to have a blood sample taken.

Lack of Access to Suitable Care

- As highlighted by HIQA in their Overview of 2016, feedback from residents in residential care settings indicate “many residents expressed a wish to be cared for in their own home.” Repeated surveys have consistently indicated that the great majority of people wish to live and die in their own home, and to receive care in their home. Research with social workers working with older people reported that while older people did not want to go to long-term residential care, many viewed their situation as not having a choice, and that it is a “necessary evil”. The research suggests that more than 50% of people in long-term residential care centres do not need to be there and could be cared for at home if adequate resources for home and community based care was provided. Without a statutory framework there is no entitlement to homecare. Due to the discretionary basis of the provision of homecare, access to homecare services can vary from one Community Health Organisation area to another creating a fragmented and underfunded system. There is no equality of access to existing homecare provision. The legislative basis of the NHSS and the lack of a statutory homecare system has created a systemic bias towards care in congregated residential care centres.

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16 Sage Support and Advocacy Service for Older People letter from Mervyn Taylor, Sage Manager to Minister Kathleen Lynch, 3rd November 2015.

17 HIQA, 2017, Overview of 2016 HIQA regulation of social care and healthcare services, Ibid 14, page 31


While residential care centres can provide care for people for whom it is their choice, and for people with specific care needs when appropriate, the State’s lack of action to create alternatives to long-term residential care has resulted in people with varying levels of care needs being admitted to a situation of detention, and being de facto detained where no other option to meet their care needs exists.\(^{21}\)

- The impact of an inaccessible homecare service impacts also on the number of vulnerable people remaining longer than necessary in acute hospital settings.\(^{22}\) Noting the financial\(^{23}\) and logistical impact of delayed discharges on the public hospital system, delays result in a person forced to remain for extended periods of time in an acute hospital setting with unsuitable everyday living conditions, where a person is subject to conditions of deprivation of liberty.

Sage Experience 2:

The following is an example of how a deprivation of liberty can occur, and is based on Sage experiences as an advocacy service working with vulnerable adults and older people since 2014.

Frank is in his 60s, is single and up to 18 months ago had lived alone in a small town in the West of Ireland with limited homecare and meals delivered. He has a lifelong medical, he experiences seizures and is at risk of the impact of these. He has good mobility. His nutrition intake was poor as he regularly did not eat the food delivered to him and his lifestyle choices were impacting on his condition. He had repeated hospital admissions linked to the condition. During a hospital admission Frank was assessed as needing long-term care to manage his condition. He was considered to not have an insight into his condition, his capacity to make a decision about long-term care was questioned and an application for wardship was considered. Based on the recommendation of healthcare professionals Frank consented to a move to a nursing home. Due to no availability he moved to a nursing home in another county away from his familiar surroundings but close to some relatives. Frank was a lot younger than the other people residing in the nursing home, his opportunities for social interaction were limited as he was living with people with advanced dementia. He had no opportunities for appropriate stimulation. The premises was secured by locked doors, he was not allowed to leave the premises without being accompanied by a member of staff. The people in charge of the nursing home were not willing to put in place less restrictive measures and allow Frank to come and go freely from the facility due to perceived risks. Frank expressed that he wanted to leave the facility and that he wanted to return to his home. Having spent four months in the facility Frank self-discharged and returned to his home. At the time of his return home there were no homecare supports in place for him. With assistance from a relative, friend and advocacy service private homecare for one hour per day was arranged, Frank paid privately for this service. With assistance from an advocacy service an application for a homecare package was made. Frank was linked with essential amenities and community/voluntary services. The homecare package assessment determined that Frank did not have sufficient care needs, and homecare was not granted. Frank’s ability to privately pay for homecare was not sustainable, and

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\(^{22}\) In December 2016, there were 436 recorded delayed discharges from acute hospital. See presentation by Michael Fitzgerald, HSE Head of Operations and Service Improvement, Services for Older People, presentation to the Irish Gerontological Society and Irish Social Policy Association Symposium on Exploring the Establishment of Statutory Homecare Services in Ireland on 26th May 2007 http://www.irishgerontology.com/sites/default/files/basic_page_pdf/M.%20Fitzgerald%2C%20Services%20for%20Older%20People%2C%20HSE.pdf [accessed 09/06/2017];

\(^{23}\) Delayed discharges were estimated to cost the State €540,000 per night (HCCI, 2013 http://www.hcci.ie/2013-08.html; Ring, E. (29th August 2013) “Delayed hospital discharges cost €500k a night”, Irish Examiner available at http://www.irishexaminer.com/ireland/delayed-hospital-discharges-cost-500k-a-night-241282.html
homecare stopped. Frank’s condition deteriorated as he needed supports, assistance with food preparation and household tasks, and prompts relating to personal care and medication. Frank was admitted to hospital. During a hospital admission Frank consented to a move to long-term care, he understood he was going to a nursing home for a respite period. Frank subsequently discharged himself from the nursing home and returned home, homecare supports were not put in place for him. He continued to live at home for two months without homecare and his overall condition deteriorated. Frank was admitted to hospital again, at times he was frustrated and attempted to leave the hospital, he was given medication to reduce his anxiety which made him drowsy, lethargic and unable to communicate coherently. Frank consented to a move to long-term care. Frank is now in a nursing home, he believes that he is in a nursing home for a period of respite. He is expressing a wish to return home. An application for wardship is being considered.

- A person may consent to receive care and treatment in a place of residence (‘relevant facility’) but not consent to the restrictions on liberty that the place of residence (‘relevant facility’) have in place.
- A person may consent to receive care and treatment but not consent to be in a particular place of residence
- A person may consent to receive care and treatment in a place of residence and may change their mind
- A person may consent to receive care and treatment on a respite period and the conditions of their care and treatment may change resulting in a deprivation of liberty
- A person may consent to receive care and treatment without all relevant information and all options being explained to the person in a way that is understandable to them
- An assessment of care needs, an assessment of capacity to consent to care and an assessment of capacity to consent to live in a ‘relevant facility’ where there is a potential deprivation of liberty are separate assessments and determinations.
- A lack of resources for appropriate care and supports in the community, and a lack of a statutory right to homecare, can result in a person being in a ‘relevant facility’ against their wishes.
- A systemic bias towards long-term care can result in a person being in a ‘relevant facility’ against their wishes
- Consideration or planning for wardship when a person has decision-making capacity, and without exploring other options, can result in an unnecessary interference and restriction on the person’s rights.

5. Main Provisions and Questions

Head 1 – Definitions

Questions on Head 1:
1.1 Do you have any views on the definitions currently included in this draft Head?

- The terms ‘Admission’ and ‘Admission Decision’ should be revised to reflect that the decisions in question will relate to a decision for a person to be in a ‘place of residence’ where they will receive care and potentially treatment.
- The definitions should reflect that the relevant person, if assessed to not have capacity to make the decision, is involved in the decision-making process in accordance with the Guiding Principles of the ADM ACT 2015
- The definitions should reflect that the decision is ‘whether or not’ a person will be in a place of residence as the outcome of the decision should not be predetermined.
- The definitions should also reflect that the decision may be subject to change, and is not for an indefinite period of time or a permanent decision that the person be in a place of residence.
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”?

- As included in the ADM Act 2015 the definition of healthcare professional should also be included in the Deprivation of Liberty Safeguards. An input from a healthcare professional is sought for applications to the court under Part 5 of the ADM Act 2015. The view of more than one medical or healthcare professional should be sought in relation to a decision which may result in deprivation of liberty.
- Sage submits that the decision whether or not a person will become a resident in a ‘relevant facility’ should not be solely based on medical evidence, input or expertise which may result in a deprivation of liberty. The requirement for medical evidence may be relevant in the context of a person admitted in relation to a mental health disorder, however it is in contravention of Article 14 of the UNCRPD to deprive a person of their liberty based on their actual or perceived impairment.\(^{24}\)
- The decision that a person should become resident in a ‘relevant facility’, and that this decision may result in the person being deprived of their liberty should be made in consultation and with the input from as broad a representation of healthcare professionals as possible with the relevant person’s involvement in the decision-making process.

1.3 Do you have any other views specific to Head 1?

- The definition of an ‘Independent Advocate’ should be included in this section.
- The definition of ‘Specified person’ should be included in this section.
- The current definition of ‘Relevant facility’ does not include a range of facilities where a person may be de facto detained and potentially deprived of their liberty:
  - Consideration should be given to acute hospitals where a person may be in receipt of care and treatment for a prolonged undefined period of time, and due to delayed discharges and the potential that delayed discharges may increase due to Deprivation of Liberty Safeguards being operationalised a person may be within an acute hospital setting for an undefined period of time, and experience restrictions on their liberty and risk being deprived of their liberty.
  - Consideration should be given to step-down and respite facilities which are operated similar to a hospital facility in some areas. A person who is receiving respite care during a period of convalescence could be in a step-down facility for an undefined period of time. Similarly step-down facilities are used for persons who have been discharged from acute hospital as they no longer have acute care needs but do not have an appropriate place to go, due to lack of space in an appropriate long term care setting or due to difficulties in obtaining homecare services, or awaiting home adaptation grants from local Government. This results in a person being in a care setting where they may be subject to the conditions of deprivation of liberty for an undefined period of time.
  - Consideration should be given to the use of respite services which operate for people with disabilities, a person may be subject to the conditions of deprivation of liberty while in respite care. A person may avail of respite services for a defined short period of time which is extended, or the short period of respite may be repeated several times.
  - Consideration should be given to supported living accommodation, and community/voluntary housing associations and bodies where a person may reside for an undefined period of time and may be subject to the conditions of deprivation of liberty.

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\(^{24}\) Committee on the Rights of Persons with Disabilities \textit{Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities} Adopted during the Committee’s 14th session, held in September 2015
Consideration should be given to potential *de facto* detention and deprivation of liberty which may occur if a person is in receipt of care in their home by a public or private provider, or care from informal carers or a combination of both.

- The definition of ‘Restraint practices’ should be strengthened to reflect that the application of restraint without consent is unlawful and is an interference with a person’s rights. The definition should reflect an interpretation of ‘exceptional circumstances’ as referred to in the draft provision under Head 2(3)(g). The definition should reflect the concepts of a restraint practice being to prevent an imminent risk of serious harm, a measure of last resort, being proportionate to the risk, necessary and least restrictive, in place for the shortest period of time, and that the views of the relevant person are respected.

**Head 2 – Application and Purpose of this Part**

**Questions on Head 2:**

2.1 Do you have any views specific to Head 2?

- Exclusion of wards from the Heads of Bill is discriminatory and not in compliance with the UNCRPD
- Under Head 2(3)(a) the term ‘reasonably believed’ to lack capacity does not adequately reflect the requirement that a person’s capacity should be assessed functionally to determine if the person has the capacity to make the relevant decision.
- Head 2(3)(a) does not adequately reflect who will assess and determine the person’s capacity to make the decision whether or not to reside in a ‘relevant facility’.
- The current wording of Head 2(3)(a) places the decision to reside in a ‘relevant facility’ (to be admitted) ahead of the process to assess the person’s capacity to make the decision itself to reside in a ‘relevant facility’.

**Head 3 – Person’s Capacity to Make a Decision to Live in a Relevant Facility in Advance of an Application to Enter the Relevant Facility**

**Questions on Head 3:**

3.1 Do you have any views specific to Head 3?

- Head 3(1) and the accompanying Explanatory Note 1 are not in line with the principles of the ADM ACT 2015 which creates a statutory presumption of capacity, states that a person’s capacity should be assessed functionally and is ‘issue specific and time specific’ that ‘...a person’s capacity shall be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at that time.’ (ADM Act 2015, Section 3(1))
- The process as outlined in Head 3 does not enable a process of capacity building with the person and supported decision-making in accordance with the ADM Act 2015 prior to the healthcare professional determining the person lacks capacity and triggering an application to court if an appointed decision-making role is not in place. Through capacity building with the person to make a decision and the support of an independent advocate, the person may appoint an assistant decision-maker or enter a co-decision making agreement to enable the person to make a decision whether or not to reside in a ‘relevant facility’. This would prevent a lengthy and costly application to Court. Through a process of capacity building a person may be enabled to create an EPA or AHCD.
- Clearer reference should be made to the Guiding Principles which should be followed in accordance with the ADM Act 2015, specifically that the person should be facilitated to participate in the decision, the person’s will and preferences should be respected, the intervention should be the least restrictive, and in place for the shortest period of time.
In making a determination in relation to a person to reside in a ‘relevant facility’, the healthcare professional should be required to outline the benefit of the intervention for the person as required in Section 36(5) of the ADM Act 2015 in relation to an application to Court. Specifically to outline what are the benefits for the person sought to be achieved by the ‘admission’, why the benefit for the person ‘…has failed to be achieved in any other appropriate, practicable and less intrusive manner…’, and why no other ‘…appropriate, practicable and less intrusive manner to achieve that benefit remains to be taken…’.

The right of access to an independent advocate and the process of engaging an advocate for a person by the healthcare professional should be included in Head 3, with access to an advocate as early as possible in the decision-making process.

The phrasing of Head 3(1)(b) implies the outcome of the decision is already determined, the decision to live in a ‘relevant facility’ is not yet made.

Head 4 – Procedure for Routine Admission of a Relevant Person to a Relevant Facility

Questions on Head 4:

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

- See Section 2 Deprivation of Liberty.
- Concepts and how these will be applied in practice will need greater exploration in guidelines or codes of practice.

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).

- The right of access to an independent advocate and process of engaging an advocate should be included as early as possible, and prior to an application to court under Part 5 of the ADM Act 2015 being made on behalf of the person. The engagement of an independent advocate as early as possible in the process would benefit the person by maximising their capacity to make the decision for themselves, or to enter a co-decision making agreement for the purpose of making a decision whether or not to reside in a ‘relevant facility’ or to create an EPA and thereby reducing the need for a lengthy and costly application to court.

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

- The term ‘routine’ is inappropriate to describe a procedure which may result in a vulnerable person being deprived of their liberty, a procedure which can result in a person being deprived of their liberty should be an exception rather than ‘routine’.

Head 5 – Procedure for Admission of a Relevant Person to a Relevant Facility in Urgent Circumstances

Questions on Head 5:

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

- Head 5(1)(a) should also include that the admission/intervention is proportionate to the significance and urgency of the matter, and that it is the least restrictive of the person’s rights and freedoms.
- Consideration should also be given to the circumstances in which a vulnerable adult or older person is admitted to a ‘relevant facility’ due to immediate care needs, or ongoing care needs on the basis
that there is no other appropriate accommodation or facility to care for their needs. The person’s needs may not be solely medical, but due to a lack of suitable alternative accommodation a person may be within a ‘relevant facility’. A person in such circumstances may be deprived of their liberty, but would not come within the safeguards of the Mental Health Act 2001 where an admission is due to a risk of harm, or the Deprivation of Liberty Safeguards.

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).

- A vulnerable adult or older person with personal, welfare and social needs with little or no access to care at home or with no reasonable alternative residential accommodation will often be accommodated in a ‘relevant facility’. A decision that a person will reside in a ‘relevant facility’ should consider all aspects of the person’s circumstances. A decision that a person will reside in a ‘relevant facility’ where they may be deprived of their liberty should not be solely based on a medical model of care, and should include input from appropriate health and social care professionals, and the person should be facilitated to participate in the decision-making process with the support of an independent advocate and the supported decision-making structures available under the ADM Act 2015.

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 right of access to an independent advocate and process of engaging an advocate should be included as early as possible following an emergency admission (‘urgent circumstances’) and prior to an application to court under Part 5 of the ADM Act 2015 being made on behalf of the person. The engagement of an independent advocate as early as possible in the process would benefit the person by maximising their capacity to make the decision for themselves, to enter a co-decision making agreement for the purpose of making a decision to reside in a ‘relevant facility’ or to create an Enduring Power of Attorney and thereby reducing the need for a lengthy and costly application to court.
- An independent advocate could have the role of contacting the Director of the Decision Support Service.
- An independent advocate could be assigned by the Director to make an application to court on behalf of the relevant person, by inclusion of ‘Independent Advocate’ in Section 35 Part 5 of the ADM Act 2015.

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

- ‘Urgent circumstances’ are not defined in the Heads of Bill, to be consistent with established terminology the term ‘emergency’ or ‘emergency admission’ could be used in line with HIQA National Standards for designated centres.
- Head 5(4) does not refer specifically to the making of an ‘admission decision’ when referring to the role of a co-decision maker, decision-making representative or attorney with authority to make decisions in relation to personal welfare matters. Suggested amendments to Section 44 and Section 62 of the ADM Act 2015 also need to be included for the role of co-decision-maker.
- Head 5(5) is not clear what safeguards are in place for a person who is the subject of an emergency admission in this circumstance, a reading the current draft implies that a formal decision that the person will reside in a ‘relevant facility’ is made by a person without the specific authority to make an ‘admission decision’.
- The timeframes outlined in this section could result in a person being arbitrarily deprived of their liberty for 5 days before they or a person specified by them is given notification of the reasons for
their detention. The timeframes also indicate that a person could be arbitrarily deprived of their liberty for up to 25 days.

- The role of the Special Visitor is not utilised in this section, the Special Visitor could be requested by the Director to meet with the person who is admitted in emergency circumstances.
- There is no maximum time period applied in the circumstance where the court orders that the temporary admission decision shall continue until the court has disposed of the application, which creates a risk of a prolonged period of arbitrary deprivation of liberty based on an initial temporary admission.

Head 6 – Procedure for Making an Admission Decision

Questions on Head 6:

6.1 Is the evidence of one medical expert sufficient?

- As stated previously inputs from a broad range of healthcare professionals should be sought when making a decision whether or not a person should reside in a ‘relevant facility’ where there is a potential deprivation of liberty. Decisions to reside in a ‘relevant facility’ should consider all of the person’s circumstances and the person’s overall care needs and risks, and not solely medical treatment. Therefore health and social care professionals such as a social worker, public health nurse, occupation therapist etc. are appropriate professionals to be consulted in relation to the relevant decision.

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

- Head 6(1)(a) should include a clearer reference to the Guiding Principles which should be followed in accordance with the ADM Act 2015, specifically that the person should be facilitated to participate in the decision, the person’s will and preferences should be respected, the intervention should be the least restrictive, and in place for the shortest period of time.
- Head 6 should allow for consideration that a person may make their own decision to live in a ‘relevant facility’ at any stage while the procedure is ongoing to seek an order from the court.
- Head 6(1) should allow for the consideration that vulnerable adults or older persons are frequently admitted to a ‘relevant facility’ for the purposes of receiving care due to age related conditions or disability, where there may not be risk of significant harm. In this context it is important that such persons can benefit from Deprivation of Liberty Safeguards. Therefore the most appropriate health and social care professionals, (social worker, occupation therapist and public health nurse) should be consulted and be involved in determining the care needs of the person and providing evidence to the court and the decision-making representative in relation to the person’s needs.

Head 7 – Persons Living in a Relevant Facility

Questions on Head 7:

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

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)

- The ADM Act 2015 provides for a statutory presumption of capacity, therefore this should be the primary consideration under this Head. If the person’s capacity to make the relevant decision is in question the person’s capacity should be assessed functionally and in accordance with the principles of the ADM Act 2015, including a process of building the person’s capacity to make the decision, through supported decision-making, or engaging in a co-decision making agreement.
- The temporary decision to prevent a person from leaving a ‘relevant facility’ is being made by one person only. Considering the risk of arbitrary deprivation of liberty due to a temporary admission it is questionable if this is the most appropriate approach.
7.3 Do you have any other views specific to Head 7?

- The right of access to an independent advocate and process of engaging an advocate should be included as early as possible, and prior to an application to court under Part 5 of the ADM Act 2015 being made on behalf of the person. The engagement of an independent advocate as early as possible in the process would benefit the person by maximising their capacity to make the decision for themselves, or to enter a co-decision making agreement for the purpose of making a decision to reside in a ‘relevant facility’ and thereby reducing the need for lengthy and costly applications to court.

- In relation to Head 7(4) to 7(8) consideration should be given to the potential interference in a person’s rights and if it is necessary and the least restrictive of the person’s rights to initiate an application to court under Part 5 of the ADM Act 2015 when a person initially consented to live in the ‘relevant facility’.

- The phrasing in Head 7(1)(a)(i) and (ii) requires that the person expresses a desire to leave the ‘relevant facility’, to ensure that the Deprivation of Liberty Safeguards are applicable to all vulnerable adults and older people this limiting phrase could be expanded to reflect that a person may express that they do not wish to be in or to live in a ‘relevant facility’ without specifically requesting to leave.

- Heads 7(9) to 7(12) provides for an application to court for review if a person regains capacity or for a review of the ‘admission decision’, which may result in a prolonged time period where a person is deprived of their liberty and prevented from leaving the ‘relevant facility’ if that is their decision. Furthermore if the person has capacity to make the decision whether or not to be in the place of residence this decision should be respected, and consideration should be given to the potential interference in a person’s rights and if it is necessary and the least restrictive of the person’s rights to initiate an application to court.

- It is not uncommon for a family member to sign a contract of care with a ‘relevant facility’ on behalf of another person, even in circumstances when the person has the decision-making capacity to do this themselves. Circumstances also arise where a person may have been coerced into making a decision to reside in a ‘relevant facility’ influenced by undue pressure from family member or health and social care personnel. A person may have made a decision to reside in a ‘relevant facility’ on the basis that they were not aware of other options available to them, and a person may have made a decision to reside in a ‘relevant facility’ due to the lack of alternative suitable accommodation to meet their needs. To ensure that the Deprivation of Liberty Safeguards are equally beneficial to all vulnerable adults and older people a process should be initiated with all persons residing in a ‘relevant facility’ to ensure a person is aware of the Deprivation of Liberty Safeguards and their consent to reside in the ‘relevant facility’ is obtained.

Head 8 – Transitional Arrangements for Existing Residents on Commencement of this Part

Questions on Head 8:
8.1 Do you have any views specific to Head 8?

- The right of access to an independent advocate and process of engaging an advocate should be included as early as possible, and prior to an application to court under Part 5 of the ADM Act 2015 being made on behalf of the person. The engagement of an independent advocate as early as possible in the process would benefit the person by maximising their capacity to make the decision for themselves, or to enter a co-decision making agreement for the purpose of making a decision to...

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reside in a ‘relevant facility’ and thereby reducing the need for lengthy and costly applications to court.

- An independent advocate could have the role of contacting the Director of the Decision Support Service.
- An independent advocate could be assigned by the Director to make an application to court on behalf of the relevant person, by inclusion of ‘Independent Advocate’ in Section 35 Part 5 of the ADM Act 2015.
- There is no indication of why a lengthy time period of 12 months and 1 day is applied in Head 8(3)
- Head 8(5)(i) should be revised to reflect the statutory presumption of capacity, the process of maximising a person’s capacity to make relevant decisions, to engage in a decision-making assistant agreement, or a co-decision making agreement, or potentially to create an EPA and an AHCD.
- Head 8(5)(ii) should be removed

Head 9 – Review of Admission Decisions

Questions on Head 9:
9.1 Do you have any views specific to Head 9?

- The review process and decision is based on medical evidence, and does not refer to a functional approach to capacity assessment as required under the ADM Act 2015 and would not be in compliance with the UNCRPD.
- As stated previously a broader representation of appropriate healthcare professionals should be consulted considering the nature of the decision that a person will reside in a ‘relevant facility’ which may result in a deprivation of liberty. As stated previously vulnerable adults and older person reside in relevant facilities in order to have care needs met due to a lack of alternative care or accommodation arrangements, such persons should also benefit from Deprivation of Liberty Safeguards.
- Consideration should be given to seeking the input of a General or Special Visitor to monitor and keep under review the degree and extent of supervision and control and lack of freedom to which the relevant person is subject in the ‘relevant facility’.
- The provision does not refer to the option for a relevant person, or a person who has a bona fide interest in the welfare of the relevant person, to make an application to court under Part 5 of ADM ACT 2015.

Head 10 – Chemical Restraint and Restraint Practices

Questions on Head 10:
10.1 Do you have any views specific to Head 10?

- The proposal to introduce Regulations prescribed by the Minister for the use of Restraint Practices is welcomed, a consultation process should be undertaken to get input and expertise on how Regulations are operationalised in practice.
- There is a need to introduce Regulations on the administration of medication to ensure that the purpose for which medication is given does not come within the provisions set out in Head 10(1).

Head 11 – Records to be Kept

Questions on Head 11:
11.1 Do you have a view on the types of records that must be kept under this Head?

- Records should be kept to document the process and steps taken to build the person’s capacity and support the person to make a decision whether or not to reside in a ‘relevant facility’ in accordance with the ADM Act 2015, including access to an independent advocate for the person.
- Records should be kept to document the process of assessing the person’s capacity using a functional approach
- Records should be kept to document the process and steps taken to adhere to the Guiding Principles of the ADM Act 2015 in making the decision whether or not the person will reside in a ‘relevant facility’
- Records should be kept regarding the administration of medication
- Records should be kept regarding restraint practices, to document what steps were taken to prevent the use of a restraint practice, what threshold was applied to allow for a restraint practice to be used, and that the restraint was to prevent an imminent risk of serious harm, was a measure of last resort, was proportionate to the risk, was necessary, was the least restrictive approach, was in place for the shortest period of time, and that the views of the relevant person were respected.

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

Head 12 – Regulations
Questions on 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?

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

12.3 Do you have any other views specific to Head 12?
- A procedure should be introduced to ensure that all persons residing in a ‘relevant facility’ are informed of their rights and safeguards in relation to consent and Deprivation of Liberty, and a procedure is undertaken to ensure that all persons residing within a ‘relevant facility’ have consented to reside there.
- Regulations should be introduced for the circumstance of a person who has capacity deciding to leave a ‘relevant facility’
- Regulations should provide for access to independent advocacy, and the appointment and functions of an Independent Advocate.

Head 13 – Offences
Questions on Head 13:
13.1 Do you have a view on the proposed offences set out in this Head?

13.2 Do you have any other views specific to Head 13?
- It should be an offence to conspire to admit a person to a ‘relevant facility’
- It should be an offence to coerce a person into making a decision to reside in a ‘relevant facility’

Head 14 - 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?
- The provisions outlined in the Heads of Bill require applications to court for ‘admission decisions’, considering the likely demand on the court there is a risk of prolonged time periods where a person is arbitrarily deprived of their liberty without timely access to a process.
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?

- The safeguards should apply equally to all people who are detained against their wish or where there is an interference to their right to liberty. To comply with the UNCRPD and principles of equality and non-discrimination it is not appropriate to treat people differently on the basis of disability, age or existence of a mental illness. As stated previously it is in contravention of Article 14 of UNCRPD to deprive a person of their liberty based on their actual or perceived impairment.
- The Heads of Bill require clarity on how the proposed legislation would interact with Mental Health related legislation by ensuring the presumption of capacity is upheld, and that the individual’s right to self-determine and right to liberty are safeguarded.