



Support & Advocacy Service

**Human Rights: Vulnerable Adults and Older People in  
Ireland**

**Submission to the United Nations Committee Against Torture  
on the Second Periodic Report of Ireland**

**UN Convention Against Torture and other Cruel,  
Inhuman or Degrading Treatment or Punishment**

**61<sup>st</sup> Session of the Committee Against Torture**

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*About Sage Support and Advocacy Service*

*Sage Support and Advocacy Service<sup>1</sup> exists to promote and protect the rights, freedom and dignity of vulnerable adults and older people through the development of support and advocacy services to address individual and systemic issues. 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. Sage was established in September 2014 and has developed in response to an identified need for the provision of support and advocacy services following documented incidents of failure within the care system, e.g. the Leas Cross nursing home abuse scandal in 2005<sup>2</sup> and the allegations of abuse brought to public attention at Aras Attracta care setting in 2014<sup>3</sup>.*

This submission is made in advance of the examination of Ireland during its second review cycle under the UN Convention Against Torture, Cruel, Inhuman or Degrading Treatment or Punishment. Ireland has opted for review by the List of Issues Prior to Reporting (LOIPR) format.

**Key Dates for Second Cycle Review:**

16 December 2013	Publication of List of Issues Prior to Reporting
23 November 2015	Submission of State Party Report
26 June 2017	Receipt of Updated Information from Civil Society
27 and 28 July 2017	Examination of State Party Report on Ireland by CAT

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*Sage Support and Advocacy Service, 26 June 2017*

## Executive Summary

1. Sage is in a unique position to bear witness to violations, which amount to inhuman or degrading treatment, of older and other vulnerable adults' rights to integrity and dignity, autonomy and self-determination. It has documented experience of *de facto* detention and deprivation of liberty encountered through interactions within the State, and bodies operating on behalf of the State, including those in receipt of State funding for the provision of services.

### Vulnerable Adults and Older People – The Situation in Ireland

2. Ireland has an aging population. In Ireland, approximately 4.5% of older people live in a congregated setting or residential care settings, commonly called nursing homes. This is approximately 40% higher than the current European average. This care is provided through a mix of public, voluntary and private provision. Only 11% of nursing homes have dedicated dementia care units with the majority being privately run nursing homes. This compares to rates of up to 33% in other European countries.
3. Currently there are 9 HSE (State Health Service) Safeguarding and Protection Teams around Ireland. A Nationwide Public Opinion Survey in 2017 on perceptions around, and treatment of, vulnerable adults showed one in two adults in Ireland experienced at least one form of abuse to a vulnerable adult, either to themselves or someone close to them.

#### I. Recognition of a Person's Capacity

4. Despite the signing into law in December 2015 of the Assisted Decision-Making (Capacity) Act 2015 [ADM (Capacity) Act 2015], this legislation has not yet been commenced. As a result, Ireland continues to operate a ward of court system under the Victorian-era paternalistic legislation *Lunacy Regulations (Ireland) Act, 1871*. **This also means that Ireland is unable to ratify the UNCRPD 10 years after signing it.** The current legal framework for substituted decision making for people deemed of "unsound mind" amounts to a complete denial of a vulnerable adult's human rights. Nonetheless, from 2012 to 2015 there was a 36% increase in wardship applications. Furthermore, people who are existing wards at the time of the commencement of the ADM (Capacity) Act 2015, and whose capacity will be reviewed to bring them within the new supported decision making regime, will be further subjected to degrading treatment as the new legislation does not grant the rights to legal aid or other representation in the reviewing court.
5. **Recommendations:**
  - **Take all necessary legislative measures to ensure the speedy ratification of the Convention on the Rights of Persons with a Disability, without reservation.**
  - **Repeal the Lunacy Regulations (Ireland) Act 1871 and commence the ADM (Capacity) Act 2015 without further delay ensuring adequate resources for implementation, and a detailed timeframe for commencement.**
  - **Immediately commence the provisions of the ADM (Capacity) Act 2015 under Section 3 and Section 8 relating to functional assessment of capacity and Guiding Principles for interventions with a person whose capacity is in question or may shortly be in question.**
  - **Amend the current legislation to ensure an entitlement to persons who are wards of court being reviewed and released from wardship under the ADM (Capacity) Act 2015 to representation and benefit from supported decision-making structures under Part 5 of the 2015 Act**

- **Ensure that arrangements for an Independent National Monitoring mechanism under the UNCRPD is in place and a mechanism for the involvement and participation of civil society organisations is established in accordance with Article 33(3) of UNCRPD.**

## II. Deprivation of Liberty

6. Ireland does not currently have any legislation, legal safeguards or procedures in place for a person whose capacity is being questioned, or who lacks capacity, to prevent the person being *de facto* detained in a care setting. This is in sharp contrast to the legal protections available to adults detained under the State's Mental Health legislation which, in Sage's experience, can lead to the inappropriate use of the wardship system to *de facto* detain a person in residential care/congregated care settings.
7. 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. Furthermore, in the absence of the commencement of the ADM (Capacity) Act 2015 there is neither a statutory obligation to use a functional approach to determine the person's capacity to consent to residence in an institution, nor a process to support and assist the person to make that decision.
8. It is also Sage's experience that many so called "voluntary" residents are *de facto* detained as buildings are commonly secured by key code locks as a safety mechanism, requiring residents to ask permission to leave.

## III. Chemical Restraint

9. Ireland does not have any legislation on the use of chemical restraint and therefore vulnerable adults are at risk of inhuman or degrading treatment or punishment through the widespread use of chemical restraint for non-therapeutic purposes. There are no legislative safeguards to prevent the use of sedation purely for the management of a person's behaviour within care settings, or safeguards for monitoring and reviewing their use to ensure that they are used for short-term intervention as a specific treatment only and not for prolonged periods. This has led to a recognised misunderstanding about the distinction between medication being used for therapeutic reasons and medication used to control behaviour. Legislative safeguards and a right of complaint and investigation to a competent independent authority are therefore urgently required to ensure that vulnerable adults are not subjected to chemical restraint.
10. **Recommendation:**  
**State to enact legislation on Deprivation of Liberty, which adequately restricts the use of chemical restraint, and is in accordance with international human rights standards and norms regarding use of detention and restraint including the UN Convention Against Torture, the UN Convention on the Rights of Persons with a Disability and the European Convention on Human Rights.**

#### IV. Lack of Access to Suitable Care

11. Findings from repeated surveys and research in Ireland have consistently indicated that the great majority of people wish to live, receive care and die in their own homes. Research also suggests that more than 50% of people in long-term residential care centres could be cared for at home if adequate resources for home and community based care was provided. However, Ireland does not have legislation which provides for a statutory entitlement to home-care. This has resulted in home-care being provided on a discretionary basis, which varies geographically, creating a fragmented, underfunded and inequitable system.
12. Government action on the provision of care for older people has mainly centred around the funding of care in private residential congregated care settings. This has resulted in people with relatively low levels of care needs being admitted to a place of *de facto* detention because no other option exists to meet their care needs. This puts the person at risk of experiencing cruel, inhuman and degrading treatment and amounts to the State ignoring a person's right to autonomy and self-determination on where they reside.
13. The lack of accessible suitable care also impacts significantly on the number of vulnerable people remaining longer than necessary in acute hospital settings with all the consequent social and health risks to the person. This is tantamount to inhuman and degrading treatment.
14. Lack of accessible suitable care can result in adults who may be vulnerable, due to long-term mental health condition or an intellectual disability and who are aging, being transferred from one institution to a new institution which focuses just on geriatric care. The result is often the loss of previously available supports and services, continuity of service, and familiarity with surroundings essential to ensure a good quality of life. This, in Sage's view, is tantamount to inhuman and degrading treatment.
15. **Recommendations:**
  - **State to immediately implement and adequately resource provision of care in the community to prevent a person being *de facto* detained and to enable people to receive care at home in accordance with their wishes and in response to their individual care needs in a timely manner, which respects, protects and upholds their human rights.**
  - **State to immediately address delayed discharge of vulnerable adults from acute hospitals, enabling timely assessments of care needs and provision of care to meet needs elsewhere in accordance with wishes, which respects, protects and upholds their human rights.**
  - **State to scrutinise and address the systemic bias towards long-term residential care for older people in congregated settings in preference to care at home or in a less institutionalised environment, from a human rights, societal and public interest perspective.**
  - **State to enact legislation to create a statutory right to care in the community or other appropriate supported environment which provides for a flexible continuum of care, addressing individual needs and respecting choice.**

#### V. Protection from Abuse

16. It is widely contended that abuse and neglect of vulnerable adults is significantly underreported in Ireland, due to lack of public awareness of what constitutes abuse, and the lack of comprehensive policy and legal safeguards to protect vulnerable adults from abuse. Although the Minister for Health recently stated that Government supports the principle and need to provide a legislative basis for the safeguarding of vulnerable adults, there is no indication of a timeframe for such legislation or a recognition of the urgent need for it.
17. Due to a lack of statutory powers the existing HSE Safeguarding & Protection Team (SPTs) do not have powers to adequately investigate allegations of abuse in privately run care centres, despite the fact that the majority of people there are State funded. This, in the view of Sage, places a person within a private residential care setting at a potentially greater risk than a person in a public setting. In Sage's experience, there are procedural gaps and inconsistencies in the practice of the SPTs around the country and, as a result, many persons in residential care/congregated settings are not adequately protected from abuse and cruel, inhuman and degrading treatment, nor given access to an independent complaints and monitoring mechanism.

#### VI. Incontinence Wear & Artificial Feeding

18. Sage is also concerned about the use of incontinence wear in care settings for convenience due to staff shortages, and the administration of artificial nutrition by tube without consent.

#### VII. Quality of Life, Physical Environment, Privacy and Dignity

19. Sage highlights that the lack of privacy and dignity for people residing in residential care/congregated settings with outdated communal style wards leads to degrading treatment.
20. Sage has highlighted that the care package provided for in fee negotiations between the National Treatment Purchase Fund (NTPF) and privately run residential care centres is frequently inadequate, particularly because it provides for 'bed and board', basic equipment and laundry services only and does not consider an individual's care or social needs. A person on a low income or State pension can therefore be deprived of access to therapeutic care, supports and mobility equipment in a private residential care centre. Given the lack of transparency of the NTPF process and the issues raised there is a need for the NTPF to be publicly accountable, and the relevant public bodies to ensure compliance with the recently enacted Public Sector Duty to protect human rights in the provision of public services.
21. **Recommendations:**
- **State to take immediate action to ensure State Agencies responding to suspicions or allegations of abuse of a vulnerable adult have a right of access to all premises and relevant documents where there is a safeguarding concern.**
  - **Adequate safeguards against abuse are fundamental to ensuring a person is protected from experiencing torture, or other cruel, inhuman or degrading treatment or punishment. The State should introduce statutory provisions to protect all people at risk of abuse, and ensure that the State's Safeguarding policies and procedures are underpinned by a robust statutory framework.**

- **State funding of NHSS through the NTPF process should be open and transparent and ensure that all persons being funded by the State for nursing home care receive equitable services which reflect a person centred approach, and the State complies with its Public Sector Duty obligations in the provision of services through State providers, and private providers contracted by the State.**

#### VIII. Education and Information

22. With the commencement of the ADM (Capacity) Act 2015 adequate resources and training should be provided to all people engaged in roles specified in the legislation, and to personnel operating under the Act. In recognition that safeguarding vulnerable adults requires a multi-sectoral response, it is Sage's view that there is a need to ensure that a function to promote education and training is provided for in any future statutory provisions relating to safeguarding and that it should be a comprehensive national training programme, including an understanding of human rights, available to all persons working with/caring for vulnerable adults.

#### 23. Recommendations:

- **To ensure adequate training is provided and resourced for specific roles within the ADM (Capacity) Act 2015, and law enforcement personnel, medical personnel, public officials and other persons who will be operating under the legislation.**
- **To ensure a function to promote education and training is maintained in the Adult Safeguarding Bill 2017, or any future statutory provisions relating to safeguarding.**
- **In recognition that safeguarding vulnerable adults requires a multi-sectoral response, and in line with priority actions identified by the *Time for Action* review, the Safeguarding Vulnerable Adults training developed by the HSE National Safeguarding Office should not only be delivered to health and social care services but should be a comprehensive national training programme, including an understanding of human rights in practice, and is available to all persons engaged in "relevant work or activities relating to vulnerable adults" as referred to in the National Vetting Bureau (Children and Vulnerable Persons) Act 2012. Training should also be available to family members and those engaged in informal care of a vulnerable adult.**
- **To ensure training requirements are adhered to the State should consider mandatory training to be introduced in tandem with the requirements to satisfy Garda Vetting requirements for any persons engaged in "relevant work or activities relating to vulnerable adults."**

#### IX. Investigation, Complaint and Redress

24. The remit of Ireland's Ombudsman's Office was recently expanded to include complaints in relation to administrative actions of private nursing homes. The Ombudsman is prevented however from pursuing complaints about "clinical judgements". Sage believes that it is necessary for the need and entitlement of all vulnerable adults to an independent advocate to be provided for in any legislation on deprivation of liberty and safeguarding to ensure that investigation, complaints and redress processes are realistically accessible to them.

25. Recommendations:

- State to extend the remit of the Office of the Ombudsman to enable complaints relating to clinical judgement to be pursued.
- State should ensure that a statutory right to independent advocacy for vulnerable adults is provided for within legislation on Deprivation of Liberty, and on Safeguarding, implementing recommendations for advocacy from the State's own reviews of person's experience of service.
- State to ensure that a process of investigation and redress for a person who has an abusive act perpetrated against them is included in any Safeguarding legislation.

X. Ratification of the Optional Protocol to CAT (OPCAT)

26. Sage calls upon the State to develop a National Preventive Mechanism and to include residential care centres/congregated settings for all vulnerable adults within its remit. As illustrated by this Report there is a need to apply the torture protection framework to these settings to prevent and highlight abuse of vulnerable adults.

27. Recommendations:

- State to take steps towards the ratification of OPCAT and establishment of a National Preventative Mechanism (NPM), and to include residential care centres/congregated settings for older people and people with disabilities in the places of detention to be monitored by the NPM.

## 1. Introduction

28. Sage Support and Advocacy Service submits that Ireland is in violation of its obligations under the United Nations Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (UNCAT) in its treatment of older people and adults who may be vulnerable. The issues raised in this submission were not previously raised in submissions from Irish NGOs in 2013 in advance of the compilation by the Committee of the List of Issues Prior to Reporting (LOIPR) on Ireland, nor do they appear in the report submitted by the State Party (January 2016).<sup>4</sup> However, the issues outlined here warrant closer scrutiny, including within the framework of international human rights treaty monitoring by the UN.
29. In making this report Sage is relying on 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. In this relatively short period of time Sage is aware of violations of older people's right to integrity and dignity, autonomy and self-determination. It has documented experience of *de facto* detention and deprivation of liberty encountered through interactions within the State and bodies operating on behalf of the State, including those in receipt of State funding for the provision of services. The report also refers to reports and research from other civil society organisations, academic institutions and statutory bodies.

### International Human Rights Legal Framework and Abuses in Care Settings

30. In his 2013 report to the Human Rights Council, the Special Rapporteur on Torture, and Other Cruel, Inhuman and Degrading Treatment or Punishment noted that "...the conceptualization of abuses in health-care settings as torture or ill-treatment is a relatively recent phenomenon."<sup>5</sup> He concluded that "[e]xamining abuses in health care settings from a torture protection framework provides the opportunity to solidify an understanding of these violations and to highlight the positive obligations that States have to prevent, prosecute and redress such violations."<sup>6</sup> This includes affording stronger legal protection and redress to victims and advocates. According to the Special Rapporteur, torture presupposes a situation of powerlessness<sup>7</sup>. Powerlessness arises in the context of dependency or control where a person receiving services in a health care or other institutional environment is heavily reliant on the service provider. The Special Rapporteur considered such experiences of powerlessness to include the deprivation of legal capacity and deprivation of liberty.

## 2. Vulnerable Adults and Older People – The Situation in Ireland

31. Ireland has an ageing population. Census 2016 results show that the population aged over 65 increased by 19% between 2011 and 2016 to 637,567. For the population aged over 85, the male population increased by 25% to 23,062 while the female population increased by 11% to 44,493. According to current population projections, by 2046 there will be between 1.3 and 1.4 million people aged over 65, and over 470,000 people aged over 80.<sup>8</sup>
32. In Ireland, approximately 4.5% of older people live in a congregated setting or residential care settings, commonly called nursing homes. This is approximately 40% higher than the current European average.<sup>9</sup> It is estimated that one-third of women and one-quarter of men are likely to spend some time in a nursing home before they die<sup>10</sup>.
33. Nursing home care in Ireland is provided through a mix of public, voluntary and private provision. According to the Irish health services regulatory body, the Health Information and Quality Authority (HIQA),<sup>11</sup> there are 580 designated residential centres for older people in the State, providing a capacity for 30,369 people. Approximately 25% of current residential care capacity relates to short-stay (respite and transitional arrangements) in public nursing homes.<sup>12</sup> The majority of these homes (437) are operated privately, with a further 122 publicly operated by the Health Service Executive (HSE), Ireland's statutory health service. 21 facilities are operated by voluntary bodies. The provision of public residential centres for older people has fallen significantly over the last 30 years from almost 50% down to 20%. Within overall provision there are 44 centres with capacity to accommodate more than 100 people.
34. According to Census 2011, 4,873 people aged 65 and over recorded that they were usually resident in a hospital.<sup>13</sup>
35. There are 1,055 residential centres providing services for adults and children with disabilities registered with HIQA operating in the State. While all designated centres are required to register with the regulatory body HIQA, 354 of these centres were still due to complete registration by the end of 2016.<sup>14</sup>
36. 13.5% of the population are recorded as having a disability, including 224,388 people over 65 years<sup>15</sup>. According to the most recently available figures, approximately 4000 people with a disability resided in an institution or psychiatric hospital.<sup>16</sup>
37. In 2011, a survey of psychiatric hospitals and units showed one third of patients were aged 65 years and over. In addition, people over 75 years recorded the highest psychiatric hospitalisation rate with 36.5% of the people aged 75 and over having been in hospital for five years or more.<sup>17</sup>
38. 55,000 people in Ireland are living with dementia, a chronic or persistent disorder of the mental processes, a figure that is expected to double by 2036.<sup>18</sup> Based on the most recently available figures, there were almost 30,000 people with dementia living in the community, with 26,413 of these aged over 65 years.<sup>19</sup>

39. Only 11% of Nursing Homes have dedicated dementia care units, and the majority are provided by the private nursing home sector. This compares to rates of up to 33% in other European countries.<sup>20</sup>
40. Currently there are nine HSE Safeguarding and Protection Teams (SPT) operating in Ireland which were formed under the HSE *Safeguarding Vulnerable Persons at Risk of Abuse Policy (2014.)*<sup>21</sup> Provision is estimated to be one third of what is required. In 2016, SPTs received reports of 7,884 cases of alleged abuse or neglect of adults (all ages).<sup>22</sup> The main categories of abuse were physical abuse, psychological abuse, financial abuse and neglect, with physical abuse being the most common abuse reportedly experienced by adults under 65 years, and psychological abuse the most common for people over 65 years.
41. In 2015 there were 424 allegations of suspected or confirmed abuse of residents in residential care settings for older people reported to HIQA by the care centre under notification requirements. This represented a 20% increase in notified allegations from 2014.<sup>23</sup> In the same year there were 1,799 notifications of an allegation of suspected or confirmed abuse of residents in designated centres for adults and children with disabilities.<sup>24</sup> For the same period HIQA received 690 independent notifications reporting concerns about designated centres from residents, advocates, relatives, healthcare professionals and employees of designated centres. The Confidential Recipient for Vulnerable Adults<sup>25</sup> received 220 concerns or complaints in 2016, 41 of these were related to safeguarding of a vulnerable adult.<sup>26</sup> A Nationwide Public Opinion Survey on perceptions around and treatment of vulnerable adults showed one in two adults in Ireland experienced at least one form of abuse to a vulnerable adult, either to themselves or someone close to them.<sup>27</sup>

### 3. Issues for Consideration under Article 2 and Article 16

#### I. Recognition of a Person's Capacity

42. The Special Rapporteur on Torture has stated that '[f]ully respecting each person's legal capacity is a first step in the prevention of torture and ill-treatment.'<sup>28</sup> Despite the signing into law in December 2015 of the Assisted Decision-Making (Capacity) Act 2015 (ADM (Capacity) Act 2015)<sup>29</sup> this legislation has not yet been commenced.<sup>30</sup> As a result, Ireland continues to operate a ward of court system under the Victorian-era legislation *Lunacy Regulations (Ireland) Act, 1871*<sup>31</sup> Furthermore, due to the delay in commencement of the provisions of the ADM (Capacity) Act Ireland has been unable to ratify the United Nations Convention on the Rights of People with Disabilities<sup>32</sup>, which Ireland signed in 2007.
43. Under the adult wardship system currently in operation, an adult becomes a ward of court following an application to the High Court or Circuit Court to decide that the person whose capacity is in question is of 'unsound' mind and is unable to manage her/his own affairs therefore requiring the paternalistic protection of the Court. The person who is subject to the wardship application has a right to object in writing and to contest the wardship application in court, but has no automatic right to be heard in Court, either personally or through an advocate, and has no entitlement to legal representation or legal aid (*See Appendix 7B: 'Challenging a wardship application*). There is no procedural transparency with regard to the wardship proceeding and the responsibility for the service of notice on the prospective ward is usually the petitioner (person who is making the application). The process of a person being taken into wardship should be viewed as direct interference with a person's right to autonomy and the inherent dignity of the person. Under this system a person loses all decision-making rights, and decisions about their welfare and property are subsequently made by a Court appointed Committee(s) under the direction of the Court.<sup>33</sup> The outdated language of the legislation which refers to the person as a 'lunatic' must also be considered degrading.
44. In the absence of an alternative legal framework, health, social care and legal professionals operating on behalf of the HSE and on behalf of the Courts Service continue to be involved in submitting and processing applications for wardship. From the period 2012 to 2015 there was a 36% increase in wardship applications submitted to the Courts Service.<sup>34</sup>
45. In Sage's experience, and as reported,<sup>35</sup> the wardship process has reportedly been used inappropriately by the HSE as a method of enabling a person to be discharged from an acute hospital when they are medically ready for discharge but have no alternative care arrangements in place. The HSE Head of Legal Services has alleged that family members were leaving their older family members in acute hospitals rather than apply for the State's Nursing Home Support Scheme<sup>36</sup> to facilitate the person's move into long-term care. Families may view the NHSS as posing a risk to inheritance and of potentially resulting in financial penalties as the person's assets are assessed in determining the contribution to cost of care in a nursing home under the scheme. An action by a family member to deliberately prolong a person's stay in acute hospital should be considered a safeguarding issue and the State should seek to protect a vulnerable adult from abuse. However, rather than seeking to protect and uphold the rights of the individual to be free from abuse, the HSE has sought to apply to bring persons into wardship to free up acute hospital

bed capacity<sup>37</sup>. Such an approach by a statutory agency to bring a person into wardship for this purpose must be viewed as an infringement of the rights of the individual in question.

### 46. From Sage Experience 1

An application for wardship was initiated for a SE 1, 80s, with a diagnosis of early stage dementia by family members on the recommendation of a social worker working with the HSE, a move to a long-term care facility was also recommended due to SE 1's level of care needs. A neighbour made a referral for SE 1 to the advocacy service over concern that SE 1's wishes were not being followed as SE 1 did not wish to move to a nursing home. Following a second assessment of capacity carried out on request of the advocate acting on behalf of SE 1, and at a time when SE 1 was out of an acute care setting, it was determined SE 1 had capacity. This resulted in the application for wardship being withdrawn. SE 1 was subsequently supported to make an Enduring Power of Attorney to appoint another person to manage and make decisions about SE 1's welfare and property when SE 1 is no longer able to make decisions for themselves. SE 1 expressed upset and anger about being made a ward of court. [Sage Annual Report Case example 15<sup>38</sup>]

47. The wardship process operates, in the absence of an alternative legal framework to protect a person who is vulnerable due to a lack of capacity to make decisions for themselves, to enable decisions to be made for the person about their welfare and property in what the High Court believes to be "in their interests". However, the person does not have a right of access to the process, or the medical evidence used to commence the process until after they are served with notice of wardship, and their right of access is in written format only as an appeal to the High Court. This means that a vulnerable person with diminishing capacity or who lacks capacity, and who has limited, weak or no support structures, or funds to pay a lawyer, will not have a realistic opportunity to object to an application for wardship or have their views, wishes, will and preference represented and/or respected in any way. Without the application of a process to guarantee that all efforts are made to ensure that the person's will and preference, beliefs and values are known and understood there is a risk that the person may be subjected to degrading treatment in violation of their human rights.<sup>39</sup> (See Appendix 7B, *Challenging a wardship application*).

48. In determining an application for wardship the Court requires medical evidence using the status "all or nothing" approach to assessing capacity. As the ADM (Capacity) Act 2015 has not been commenced there is no statutory requirement that a person's decision-making capacity is to be assessed using a functional approach ("...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").<sup>40</sup>

49. Furthermore, even with the commencement of the ADM (Capacity) Act when all wards of court will have to be reviewed and brought within the supported decision-making structures of the 2015 Act those individuals will be further disadvantaged as the review process for existing wards under the 2015 Act does not provide for an entitlement to legal aid or to be provided with a Court Friend to represent the ward or express their will and preferences to the reviewing court. For existing wards, this continues the risk of being further subjected to degrading treatment in violation of their human rights.<sup>41</sup>

### 50. Recommendations:

- **Take all necessary legislative measures to ensure the speedy ratification of the Convention on the Rights of Persons with a Disability, without reservation.**
- **Repeal the Lunacy Regulations (Ireland) Act 1871 and commence the ADM (Capacity) Act 2015 without further delay ensuring adequate resources for implementation, and a detailed timeframe for commencement.**
- **Immediately commence the provisions of the ADM (Capacity) Act 2015 under Section 3 and Section 8 relating to functional assessment of capacity and Guiding Principles for interventions with a person whose capacity is in question or may shortly be in question.**
- **Amend the current legislation to ensure an entitlement to persons who are wards of court being reviewed and released from wardship under the ADM (Capacity) Act 2015 to representation and benefit from supported decision-making structures under Part 5 of the 2015 Act**
- **State to ensure that arrangements for an Independent National Monitoring mechanism under the UNCRPD is in place and a mechanism for the involvement and participation of civil society organisations is established in accordance with Article 33(3) of UNCRPD.**

## II. Deprivation of Liberty

51. Ireland does not currently have adequate legislation and procedures prescribed in law to address deprivation of liberty. For a person whose capacity is being questioned or who lacks capacity, there are no adequate legal safeguards and procedures to prevent the person being *de facto* detained in a residential care setting/nursing home/designated centre for people with disabilities/hospital other than a High Court Habeus Corpus application.
52. The Department of Health introduced the Disability (Miscellaneous) Provisions Bill 2016<sup>42</sup> which, according to the explanatory memorandum accompanying the publication of the legislation will include provisions relating to deprivation of liberty “[t]o provide legislative clarity with regard to who has statutory responsibility for a decision that a patient in a nursing home or similar residential care facility should not leave for health and safety reasons and what appeals process should be in place.”<sup>43</sup> However, the proposed legislation has since passed the second stage<sup>44</sup> of the legislative process without the wording of these provisions being included in it. Concern about this development has been raised widely, including by the Irish Human Rights and Equality Commission (IHREC) that the current timeframe for completing the legislative process does not give adequate time for the IHREC and civil society to analyse and respond to any proposed provisions before the Bill completes its passage through the Oireachtas (parliament).<sup>45</sup>
53. Due to the current lack of legislative safeguards there is no process of automatic review to determine if a person admitted to a residential care centre has consented to be there, and be subject to the institutional supervision related to this. This is in sharp contrast to the legal protections available to adults detained under the State’s Mental Health Act 2001.<sup>46</sup> 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 leading to a loss of a place to live<sup>47</sup>. 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. The research highlighted the lack of a standardised practice and approach across the State.<sup>48</sup>

*“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<sup>49</sup>*

54. Furthermore, in the absence of the commencement of the Assisted Decision-Making legislation there is neither a statutory obligation to use a functional approach to capacity to determine the person’s capacity to consent to residence in an institution, nor a process to support and assist the person to make that decision. The 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.
55. In 2010, representatives of the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) visited a disability service run by the HSE and registered with the Mental Health Commission. In their report representatives stated “...many of these so-called voluntary residents were *de facto* detained: they lived in a closed unit and were not allowed to leave the institution without prior permission.”<sup>50</sup> This experience is replicated in many residential care settings for older people where buildings 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.

**56. Account 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 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."<sup>51</sup>

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.

### III. Chemical Restraint

57. Ireland does not have legislation on the use of chemical restraint. There are no legislative safeguards to prevent the use of sedation purely for the management of a person's behaviour for convenience within care settings. These care settings include residential care centres/congregated settings for older people, for people with disabilities, hospitals, or a person's home. There are no legislative safeguards to ensure the continued monitoring and review of the use of sedation, and of antipsychotic medications for short-term intervention as a specific treatment only, and not for prolonged use, as continued use risks serious harm to the person.<sup>52</sup>
58. 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."<sup>53</sup> HIQA's guidance on restraint for residential care centres states "(a) dministering 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."<sup>54</sup> The Irish Medical Council<sup>55</sup> 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"<sup>56</sup> 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.<sup>57</sup> In light of this, legislative safeguards and a right of complaint and investigation to a competent independent authority is required to ensure vulnerable adults are not at risk of chemical restraint which amounts to inhuman or degrading treatment of punishment.
59. 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.<sup>58</sup> 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 recently highlighted to a hospital administration the use of sedation in response to a patient's refusal to have a blood sample taken.

### 60. Account 2

Sabina Brennan, Trinity College Dublin, spoke about her mother's experience at the Sage Forum on Long Term Care on 15<sup>th</sup> June 2016. She recounted how her mother who had a dementia was chemically restrained in an acute hospital.

Sabina had arranged to visit her mother in the morning, her mother was interactive during this period. She found her mother in her room on her own, in a chair beside her bed with her knuckles on the floor and she was slumped over, her mouth open and drooling. Her mother was aware and very distressed. With slurred speech, she asked her daughter "what's wrong with me, I can't talk or move, I don't know what's happening to me." When Sabina asked the nurse on duty why her mother had been sedated she was told that it was because her mother had been walking up and down the ward corridor asking to go home. She was in a locked general ward for older patients.

On another occasion, her mother was admitted to hospital with an acute illness and requiring antibiotics. While waiting for her mother to be brought up to the ward Sabina noticed that her mother was beginning to behave in a way that might need careful management. Once her mother had been admitted Sabina called to let the ward manager know that she would come in to help manage behaviours if necessary. The ward manager told her he was running a busy ward and his role was to keep her mother fed, hydrated and medicated and anything beyond that was not his responsibility. When Sabina visited later that day she found her mother heavily sedated and unresponsive in bed. On admission she had been fully alert, aware of her surroundings and able to hold a conversation. The following morning she called the ward again to see how her mother was. She was told her mother had had a difficult night trying to get out of bed and the nurse was going to give her sedation. When Sabina asked for the medical reason for the sedation she was told that her mother needed a 'special' to sit with her for safety reasons and due to staffing issues, none was available. Sabina questioned the response of the nursing staff asking if they would sedate a younger patient or a child who tried to get out of bed. When she arrived at the hospital within 30 minutes of the call a 'special' had been assigned to be with her mother.

### 61. Recommendations:

**State to enact legislation on Deprivation of Liberty, which adequately restricts the use of chemical restraint, and is in accordance with international human rights standards and norms regarding use of detention and restraint including the UN Convention Against Torture, the UN Convention on the Rights of Persons with a Disability and the European Convention on Human Rights.**

## IV. Lack of Access to Suitable Care

62. 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."<sup>59</sup> 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.<sup>60</sup> 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".<sup>61</sup> 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. Ireland does not have legislation governing the provision of home care, and without

a statutory framework there is no entitlement to home-care. Due to the discretionary basis of the provision of home care,<sup>62</sup> access to home care services can vary from one geographical (Community Health Organisation CHO) area to another creating a fragmented and underfunded system.<sup>63</sup> There is no equality of access to existing home care provision. The legislative basis of the NHSS and the lack of a statutory home care system has created a systemic bias towards care in congregated residential care centres.<sup>64</sup>

63. Government action on the provision of care for older people has previously been to incentivise the building of private residential care centres/congregated settings,<sup>65</sup> increasing funding for NHSS, and making relatively modest funding changes to home care services through home care packages and home help service.<sup>66</sup> 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 care 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.<sup>67</sup> In the view of Sage this action puts the person at risk of experiencing cruel, inhuman and degrading treatment and interfering with their right to autonomy and self-determination.<sup>68</sup> This policy also runs contrary to the policy relating to people with disabilities, where resources are made available to move people from congregated settings to independent living arrangements.<sup>69</sup>
64. Current figures show 4,600 people are waiting for a home care support. The impact of an inaccessible home care service impacts also on the number of vulnerable people remaining longer than necessary in acute hospital settings.<sup>70</sup> The degrading term 'bed blocker' was used by the HSE to describe 'delayed discharges' implying that older people awaiting long-term care were a cause of the acute hospital overcrowding crisis. In November 2016, a memo circulated and subsequently withdrawn by the HSE suggested nurses could use "minimum force" to remove a person who was medically fit for discharge but refused to leave as they "...are committing a trespass..."<sup>71</sup> As has been highlighted earlier in this report, there is inappropriate use of the wardship system in an effort to remove vulnerable older people from acute hospitals (see para. 42). The HSE has stated that this is not policy, however it is indicative of how systemic failings can lead to the degrading treatment of older people and the risk of cruel and inhuman treatment of a vulnerable person. Noting the financial<sup>72</sup> 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, increased risk of infection, lack of therapeutic and social activity, risk of clinical complications due to lack of movement, risk of loss of ability to complete activities of daily living, risk of institutionalisation, lack of stimulation and lack of basic comforts confounded by existing vulnerabilities due to age related frailty and cognitive impairment. This is tantamount to inhuman and degrading treatment as illustrated by the NIHRC's interpretation of CPT Standards in its 2012 report *In Defence of Dignity*<sup>73</sup>.

*"F1 felt bullied into moving their parent"*

*From Sage Qualitative Analysis, Annual Report 2016<sup>74</sup>*

65. There is an overreliance on long-term residential care, particularly through private providers, which is not the general public's preference.<sup>75</sup> There is a lack of alternative flexible models of care to respond to a person's individualised needs and quality of life considerations to enable a person to live with dignity according to their wishes.<sup>76</sup> In circumstances where residential care setting is appropriate, or decongregation to community living is not appropriate for the person, but some care is required for age related conditions, there is a complete lack of suitable care settings. The impact on adults who may be vulnerable, due to long-term mental health condition, or an

intellectual disability and who are aging, is a transfer from a State supported residential centre where they have access to therapeutic and social activities and benefit from skilled care staff to a State supported placement in a private or public residential care centre for older people. Due to the focus on geriatric care in nursing homes many residential care centres for older people are unsuitable and unable to meet the needs of a person with complex and multi-disciplinary care needs. Accessibility to medical and allied health disciplines for a person in a nursing home is through community based primary care and mental health teams, similar to a person living in their own home. The overall effect for such a person is a transfer from one institution, which was their home for many years and which catered for their mental health or other complex needs, to another new institution with loss of such supports and services, continuity of service, familiarity with surroundings essential to ensure their care needs are met and of a good quality of life.

#### 66. Sage Experience 2:

SE 2, in his 50s, lived in a semi-independent unit with mental health services. SE 2 was moved to a residential care centre for older people following a period in acute hospital. SE 2 was considered too high risk to return to semi-independent accommodation and no suitable option was available.

#### 67. Recommendations:

- **State to immediately implement and adequately resource provision of care in the community to prevent a person being *de facto* detained and to enable people to receive care at home in accordance with their wishes and in response to their individual care needs in a timely manner, which respects, protects and upholds their human rights.**
- **State to immediately address delayed discharge of vulnerable adults from acute hospitals, enabling timely assessments of care needs and provision of care to meet needs elsewhere in accordance with wishes, which respects, protects and upholds their human rights.**
- **State to scrutinise and address the systemic bias towards long-term residential care for older people in congregated settings in preference to care at home or in a less institutionalised environment, from a human rights, societal and public interest perspective.**
- **State to enact legislation to create a statutory right to care in the community or other appropriate supported environment which provides for a flexible continuum of care, addressing individual needs and respecting choice.**

## V. Protection from Abuse

68. It is widely contended that abuse and neglect of vulnerable adults is significantly underreported in Ireland, due to lack of public awareness of what constitutes abuse, and lack of comprehensive policy and legal safeguards to protect vulnerable adults from abuse.<sup>77</sup> The IHREC has called for the State to establish the reasons why there is a significantly lower reported rate of elder abuse compared to other countries.<sup>78</sup>

69. There is no legislative framework to provide safeguards to protect vulnerable adults from abuse, to ensure a standardised process of reporting and investigation of allegations of abuse by an independent body with authority, and to ensure an outcome and redress for the person affected by the abuse. There have been repeated calls for the introduction of safeguarding legislation, including by HIQA<sup>79</sup>. There is no adequate independent monitoring of care provision outside of

designated residential centres leaving vulnerable people at risk of abuse and cruel, inhuman and degrading treatment through substandard care.<sup>80</sup> The current policies and protocols in place are not adequately protecting vulnerable adults from abuse which was highlighted by the RTE Primetime Investigates television programme *Inside Bungalow 3* (see Appendix 7A) into abuses within Áras Attracta, a residential centre for people with disabilities. This inadequacy is also illustrated by incidents of abuse reported to HIQA and identified through the HIQA inspection process of designated centres for older people, and designated centres for people with disabilities and children (see Appendix 7C).

70. Recently, a Private Members 'Adult Safeguarding Bill' was introduced to the Seanad, the upper house of the Irish legislature<sup>81</sup> and passed the second stage of the legislative process on 5<sup>th</sup> April 2017. Although the proposed Bill received support of all Government parties, and the Minister for Health stated "...Government supports the principle of providing a legislative basis for the safeguarding of vulnerable adults"<sup>82</sup> there is no indication of a timeframe for pre-legislative considerations as outlined by the Minister, nor for progression of the Bill through the legislative process.
71. The HSE *National Safeguarding Vulnerable Persons at Risk of Abuse Policy, 2014*<sup>83</sup> (*HSE Safeguarding Policy*) promotes a 'no tolerance' approach to any form of abuse and a culture to support this within social care services for older people and vulnerable adults, and outlines a process for responding to allegations of abuse by services and the Safeguarding and Protection Teams (SPT).<sup>84</sup> The stated scope of the policy is that it is for all statutory and public funded non-statutory services providers, it is applicable across all service settings and to directly provided HSE services, and it is relevant in the community or situations where formal health and social care services are not in place.<sup>85</sup> Under the HIQA regulations<sup>86</sup> for designated centres there is a requirement to notify HIQA of an allegation of abuse, suspected or confirmed, however HIQA does not have the remit to investigate the allegation. There is no requirement in the Regulations to report an incident or allegation of abuse to the HSE, responsibility to investigate an incident or allegation of abuse is with the person in charge or registered provider. A *Trust in Care, 2005*<sup>87</sup> policy was developed for Health Service Providers with a procedure for managing allegations of abuse against staff members in a human resources context. According to the policy the Provider has responsibility for investigating allegations of abuse and determining any follow up action if an incident of abuse has been found to occur which has been perpetrated by a member of staff. There is no requirement within the *Trust in Care* policy for the Provider to notify the HSE of an allegation or incident of abuse. If there are grounds to suspect a criminal act has occurred this is referred to An Garda Síochána (Police) and an internal independent investigation is also carried out. A reform of this policy has been recommended<sup>88</sup>, as issues in relation to transparency for reporting safeguarding concerns to the HSE under this policy are evident.
72. The differing mechanisms for reporting and responding to incidents and allegations of abuse leads to ambiguity. Although private providers may adhere to the *HSE Safeguarding Policy* and have a Designated Officer (DO), it is not a mandated requirement and there is discretion applied. The majority of residents within privately operated residential care settings receive funding for their care from the State under the NHSS, however the State body HSE SPTs do not have statutory powers to adequately investigate and enter a private residential care centre without the permission or invitation of the provider. Therefore they can in principle be refused entry to meet with a person who has experienced abuse. A private nursing home provider can refuse entry of a person to the building and thereby prevent a resident in their care from accessing a service, such as independent advocacy provided by organisations like Sage.

## Nothing about you / without you

73. In Sage's experience, such procedural gaps and ambiguities in implementing the *HSE Safeguarding Policy* around the country do not adequately protect a person in a residential care setting from abuse and cruel, inhuman and degrading treatment, and do not give a person access to an independent complaints and monitoring mechanism. This, in the view of Sage, places a person within a private residential care setting at a potentially greater risk than a person in a public setting. Considering the majority of people within private residential care settings are supported financially by the State through the NHSS, the State has a responsibility to ensure that a person is prevented from abuse in the service. The State should have responsibility for responding to allegations or suspicions of abuse within the care centre. Sage's understanding is that the anomaly could be rectified by Ministerial Order. Due to the complexities of abuse where a person is dependent on another for basic care within a place of detention it is imperative that the State's bodies with responsibility for Safeguarding should have a right to access and speak with a person where there is an allegation of abuse. It should be ensured that adequate safeguards for protection, and procedures for response, are applied to uphold the rights of the individual at risk of detention, or experiencing cruel, inhuman or degrading treatment.
74. The IHREC has also expressed concern that changes to the structures of services in the area of elder abuse and safeguarding, and to the collection of data on elder abuse has led to reduced transparency on the levels of abuse and the State's response to combat abuse.<sup>89</sup>

## VI. Incontinence Wear and Artificial Feeding

75. The use of incontinence wear for the convenience of staff, and the denial of intimate care to a person is degrading and a violation of a person's dignity. It has been highlighted that incontinence wear is used in acute hospital settings due to staff shortages to facilitate a person to go to the toilet.<sup>90</sup> The prolonged use of incontinence wear can lead to permanent incontinence. The availability of long lasting incontinence pads risk their prolonged use for convenience. As highlighted by individual reports to HIQA and as reported in the Primetime Investigates programme 'Inside Bungalow 3', people are subjected to cruel, inhuman and degrading treatment by being left in soiled continence wear for periods of time, not receiving intimate care when needed after an incident of incontinence, and being encouraged to use incontinence wear when a person is continent (See Appendix 7C).
76. Sage raises concerns over of the administration of artificial nutrition by tube (PEG feed) inserted without the person's consent in circumstances where a person's capacity is at the time in question, or the person is determined to lack capacity. The administration of PEG feed to a person, in such circumstances without using either a functional approach to capacity assessment combined with supported decision-making, where required, can result in medical treatment being administered without obtaining a person's consent or contrary to a person's preciously expressed wishes. This is a violation of a person's autonomy, bodily integrity and constitutes cruel, inhuman and degrading treatment. Despite policies and professional practice guidance on obtaining consent<sup>91</sup>, a lack of a statutory obligation to use the functional approach to capacity assessment and to support decision-making puts people at risk of cruel, inhuman and degrading treatment through initial and prolonged treatment without valid consent.

*"That P3 did not want to die and that P3 did not wish to be peg fed, that P3's repeated tearing out of the tube [for] feeding was a clear form of communication that P3 did not wish to be fed in this way and P3 expressed this very clearly and verbally on every occasion that our advocate met P3."*

*From Sage Qualitative Analysis, Annual Report 2016<sup>92</sup>*

## VII. Quality of life, physical environment, privacy and dignity in care settings

77. Many of the older public residential care centres for older people and vulnerable adults have been given an extension of the period up to 2021 to meet the Standards of HIQA regulation for a designated centre. Therefore they retain the old communal 'Nightingale Wards' devoid of privacy for a person requiring assistance with a hoist, or a person requiring to use a portable toilet due to a lack of accessible facilities. This lack of privacy can result in the degrading experience of a person using a commode style portable toilet on one side of a curtain or screen while on the other side a person may be eating their dinner. In Sage's view this practice is not much better than the practice, now being ended, of 'slopping out' in prison. (See Appendix 7C).
78. The current model of fee negotiations between the National Treatment Purchase Fund (NTPF)<sup>93</sup> and residential care centres is considered unsatisfactory, particularly, because it provides for 'bed and board' and basic equipment and laundry services only.<sup>94</sup> The NTPF fee takes no account of different individual support and care needs, or any social and support needs for a person in residential care. A person on a low income or State pension can therefore be deprived of access to therapeutic care, supports and mobility equipment, unless the person can pay for it themselves. Under the revised *National Standards for Residential Care Settings for Older People in Ireland, 2016*<sup>95</sup> there is a focus on quality of life for residents and a person-centred approach to care for all residents.<sup>96</sup> The *Standards* require a level of personalised care provision which is beyond the minimum care levels funded under the NTPF agreement. This shortfall is often met by a standard charge for 'activities/services' levied on all residents regardless of the person's individualised care needs and any additional services and supports they are actually receiving.<sup>97</sup> As highlighted by Sage the fact that the care package provided for in the NTPF negotiated fee is frequently inadequate to meet the actual care needs of individuals is a matter of grave concern.<sup>98</sup>
79. The exclusion from the Nursing Home Support Scheme package of therapies, specialised seating, aids and equipment impacts significantly on many people in a residential care centre both in terms of their care and the impact on their finances. While there is provision for a needs assessment for a person, this does not translate into the contracts for care or the related pricing structure. This effectively undermines the person-centred approach and 'money follows the person' principle articulated by the HSE.<sup>99</sup> In Sage's experience once a person is in a private nursing home, there is little or no access to primary care professionals, including physiotherapy, occupational therapy, social work and essential equipment unless the person can pay for it themselves. This is contrary to national policy to promote equal access to primary care services regardless of place of residence and falls far short of the level of care generally aspired to by society. The pricing system makes no provision for basic personal care needs such as incontinence wear which amounts to a fundamental denial of human dignity. Lack of disposable income therefore curtails participation in social life and leads to institutionalisation, dependency and isolation.<sup>100</sup>
80. As pricing contracts are a matter for agreement between the NTPF and the nursing home in question and neither the Department of Health nor the HSE can influence the process, a question arises as to who is responsible for monitoring the link between nursing home charges and the quality of life of residents and the role of additional charges/'top-up' fees levied<sup>101</sup>. There is a need for further analysis and debate around the fact that public nursing homes are more expensive in comparison to the private sector<sup>102</sup> which is critical in the context of ensuring both value for money and high quality care.<sup>103</sup> Considering the increasingly complex needs of people being cared for within residential care settings, adequately resourcing the actual cost of care including skilled

and trained care staff is essential to the delivery of a person centred care model<sup>104</sup> and meeting quality of life considerations. As discussed by Dr Browne, given the lack of transparency of the NTPF process, and the issues raised there is a need for the NTPF to be publicly accountable and reviewed.<sup>105</sup>

**81. Recommendations:**

- **State to take immediate action to ensure State Agencies responding to suspicions or allegations of abuse of a vulnerable adult have a right of access to all premises and relevant documents where there is a safeguarding concern.**
- **Adequate safeguards against abuse are fundamental to ensuring a person is protected from experiencing torture, or other cruel, inhuman or degrading treatment or punishment. The State should introduce statutory provisions to protect all people at risk of abuse, and ensure that the State's Safeguarding policies and procedures are underpinned by a robust statutory framework.**
- **State funding of NHSS through the NTPF process should be open and transparent and ensure that all persons being funded by the State for nursing home care receive equitable services which reflect a person centred approach, and the State complies with its Public Sector Duty<sup>106</sup> obligations in the provision of services through State providers, and private providers contracted by the State.<sup>107</sup>**

## 4. Issues for Consideration under Article 10

### VIII. Education and Information

82. With the commencement of the ADM (Capacity) Act 2015 and the significant change in approach to capacity assessment and supported decision-making, adequate training should be available and mandated for specific roles within the legislation, and law enforcement personnel, medical personnel, public officials and other persons who will be operating under the legislation
83. The independent review of the quality of care provided in Áras Attracta, *Time for Action*<sup>108</sup> made several recommendations for action in relation to training in the context of support services to people with an intellectual disability. In Sage's view these recommendations are equally applicable to support services for older people, particularly in relation to recommendations for human rights and safeguarding training. This would be in line with the implementation of the HSE *Safeguarding Policy* which all social care services should subscribe to and implement. In recognition that safeguarding of vulnerable adults requires a multi-agency and multi-sectoral response, the HSE established the National Safeguarding Committee whose "overarching remit is to support the development of a societal and organisational culture which promotes the rights of persons who may be vulnerable and safeguards them from abuse."
84. **Recommendations:**
- **To ensure adequate training is provided and resourced for specific roles within the ADM (Capacity) Act 2015, and law enforcement personnel, medical personnel, public officials and other persons who will be operating under the legislation.**
  - **To ensure a function to promote education and training is maintained in the Adult Safeguarding Bill 2017<sup>109</sup>, or any future statutory provisions relating safeguarding.**
  - **In recognition that safeguarding vulnerable adults requires a multi-sectoral response, and in line with priority actions identified by the *Time for Action review*<sup>110</sup>, the Safeguarding Vulnerable Adults training developed by the HSE National Safeguarding Office should not only be delivered to health and social care services but should be a comprehensive national training programme, including an understanding of human rights in practice, and is available to all persons engaged in "relevant work or activities relating to vulnerable adults" as referred to in the National Vetting Bureau (Children and Vulnerable Persons) Act 2012<sup>111</sup> Training should also be available to family members and those engaged in informal care of a vulnerable adult.**
  - **To ensure training requirements are adhered to the State should consider mandatory training to be introduced in tandem with the requirements to satisfy Garda Vetting requirements for any persons engaged in "relevant work or activities relating to vulnerable adults."**

## 5. Issues for Consideration under Article 12, Article 13 and Article 14

### IX. Investigation, Complaint & Redress

85. As acknowledged by The Office of the High Commissioner for Human Rights older persons ‘often fear to report...because of their dependency on the abuser, concern for repercussions, anxiety over a lack of support or lack of familiarity or the accessibility of reliable mechanisms.’<sup>112</sup> The Office of the Ombudsman investigation into the handling of complaints by public hospitals found people were not aware how to make a complaint, feared repercussions and had a lack of confidence that anything would change.<sup>113</sup>
86. Due to the delay in commencement of the ADM (Capacity) Act 2015, lack of legislation relating to safeguarding vulnerable adults at risk of abuse and legislation on deprivation of liberty, there is a lack of an appropriate complaints, investigation and process of redress for people affected. HIQA does not have a remit to respond to individual complaints, or any investigative function in relation to individual complaints. The HSE’s *Your Service Your Say* is limited to responding to complaints about administrative practice, delays or failing to take action, that adversely affects the person, but cannot receive a complaint about a matter relating solely to clinical judgement.<sup>114</sup>
87. The Office of the Ombudsman’s remit is to examine complaints about Public Bodies, and from 24<sup>th</sup> August 2015 the remit was expanded to respond to complaints in relation to the administrative actions of private nursing homes. However, the Office of the Ombudsman is prevented from pursuing complaints where the action relatedly solely to a ‘clinical judgement’ decision. This failure in the system to adequately uphold rights to an independent complaints and investigation process is highlighted by the Ombudsman as “*frustrating for complainants and leaves them with many unanswered questions*”<sup>115</sup>. He notes the removal of this constraint is currently under review by the Department of Health.<sup>116</sup>
88. **Recommendations:**
- **State to extend the remit of the Office of the Ombudsman to enable complaints relating to clinical judgement to be pursued.**
  - **State should ensure that a statutory right to independent advocacy for vulnerable adults is provided for within legislation on Deprivation of Liberty, and on Safeguarding, implementing recommendations for advocacy from the State’s own reviews of person’s experience of service.**<sup>117</sup>
  - **State to ensure that a process of investigation and redress for a person who has an abusive act perpetrated against them is included in any Safeguarding legislation.**

## 6. Optional Protocol to the Convention Against Torture (OPCAT)

### X. Ratification of the OPCAT

89. Ireland has not ratified the Optional Protocol to the UN Convention against Torture (OPCAT) signed on 2<sup>nd</sup> October 2007. No National Preventive Mechanism, as provided by OPCAT, to independently monitor places of detention has been established or designated. Reference was made to the role of HIQA as an inspection body for places of detention in the State's Second Periodic Report in November 2015. HIQA does not have a remit that includes all of the functions of a NPM.<sup>118</sup> As stated previously, the Office of the Ombudsman responds to administrative complaints, and does not have a remit that includes the functions of a NPM. The remit of the proposed Criminal Justice Inspectorate by the Department of Justice and Equality would not, given its focus on criminal justice matters, be an appropriate body to bear the functions of a NPM which must include responsibility to monitor residential care centres for older people and people with disabilities. At present, Ireland's existing inspection, complaints and safeguarding mechanisms are neither adequate nor equipped to act in a preventive role in relation to incidents of cruel, inhuman and degrading treatment. There is a pressing need for a mechanism which will apply the torture protection framework to residential care settings/congregated settings to prevent and highlight violations.

#### 90. Recommendations:

- **State to take steps towards the ratification of OPCAT and establishment of a National Preventative Mechanism (NPM), and to include residential care centres/congregated settings for older people and people with disabilities in the places of detention to be monitored by the NPM.**

## 7. Appendices

### A. Áras Attracta

Áras Attracta, run by the Health Service Executive (HSE), is a congregated residential setting for adults with intellectual disabilities, based in Swinford, Co. Mayo. 'Inside Bungalow 3', was a RTE Investigations Unit programme for *Prime Time current affairs news programme*<sup>119</sup> which was broadcast on national television on 9<sup>th</sup> December 2014. The footage from inside the residential setting was taken by an undercover reporter working as a student care worker over several months. The footage showed seven women with intellectual and physical disabilities being subjected to abuse, including force feeding, slapping, kicking, physical restraint and shouting. One of the people documented in the report is largely confined to one of two chairs. She experiences the following over this period: she is physically pushed into a chair and told to stay in the chair or go to bed; she is intimidated and shouted at by staff; a male staff member sits on top of her and she tries to push him away, she is then told to apologise to the staff member; when she is displaying some challenging behaviour a staff member grabs her by her clothing pulling her from the chair and drags her along the floor; when she indicates that she wants to use the toilet a staff member responds "If you died I won't bring you to the toilet, I haven't a notion", she is then refused assistance by a second member of staff, and is told "You won't go because you are bold [i.e. naughty]".

A HIQA inspection of the facility conducted in February 2014, identified several actions for follow up. These actions related to "nutrition, the use of restrictive practices and provision of training to all staff on the protection and safeguarding of residents from abuse."<sup>120</sup> A follow-up inspection in May 2014 noted significant improvements relating to these areas. A subsequent inspection in January 2015 noted issues relating to the use of medication to manage behaviour; bathroom and toilet facilities in some of the bungalows did not have arrangements in place to ensure the residents could use the facilities in private; staff did not have sufficient understanding of the importance of the privacy of residents' bedrooms. The inspector saw evidence that chemical restraint, in the form of hypnotics, (medications used to aid sleep), were used to manage nocturnal behaviour.<sup>121</sup>

Speaking at the time on the *Prime Time* television Programme the then Minister for State at Department of Health, Kathleen Lynch, said "I refuse to believe Áras Attracta is the only place where this is happening."

Findings from the review<sup>122</sup> showed that for residents in Aras Attracta "...their expectations, hopes and aspirations are very much limited by the horizons of that world – a congregated setting....life in Áras Attracta is characterised by inactivity, lack of stimulation, and dependency on the support of staff for many of the things that most people take for granted. Residents have little opportunity to realise their potential to live the rich and satisfying lives that they have a right to aspire to."<sup>123</sup>

There was a lack of awareness among some staff of the basic human rights of individuals with disabilities. The Review Group stated that "[t]here are restrictions on the rights of some residents – for example, in the use of psychotropic medication in the management of behaviour. There was limited knowledge among some staff as to why such medication might be prescribed – the staff member responsible for one resident was unable to confirm whether or not the resident had a psychiatric diagnosis, whether or not the medication was effective, or what the possible side effects might be."<sup>124</sup> For one person subject to a restrictive practice there was no evidence the restriction

was given due process consideration, was independently reviewed or time-limited. There were some locked areas, accessible only by staff with knowledge of the code.<sup>125</sup>

The Review Group recommended a move to rights-based model of service delivery, and noted that the model of service in Aras Attracta promoted dependence, did not equip people to make decisions about their own lives, did not take account of the individual's potential, and failed to respect the dignity and rights of individuals and noted "[t]hese are all characteristics of an institutionalised congregated setting."<sup>126</sup> The Review Group also recommended that the voices of residents need to be facilitated, listened to, and promoted and strengthening and enhancing the leadership and management.

The HSE has taken steps to respond to the Review Group recommendations, and a National Task Force was established in 2014 to lead a six-step system wide programme of measures to enhance service quality and improve safeguarding practice in disability services.<sup>127</sup> Staff found to be responsible for abuses in Áras Attracta were convicted of assault, and orders were issued by the Court to pay compensation to victim's personal funds.

### B. Challenging a wardship application.

MB, in her early 90s, was a patient in an acute hospital for 18 months, she had significant physical frailties, was unable to walk, and was limited in what she could eat but was not being treated medically. An application for wardship was made for MB by the HSE as MB was indicating that she wanted to live at home. The staff attending to her care did not think she lacked capacity. Using a functional approach to decision-making on the decision to move home with support from an advocate, MB determined that she could not go home and she agreed to move to a residential care setting where she had a family member. Using a functional approach to decision-making in relation to her finances with the support of an advocate MB decided how she would make arrangements for her business to be continued with a family member. On instruction from MB Sage attempted to stop the wardship application, informed the Office of the ward of court of MB's wishes to challenge the wardship application, and was informed a date had been scheduled for a High Court hearing of the application for wardship. Sage informed the hospital that MB had agreed to move to a residential care setting, the hospital determined this could not happen without a formal capacity assessment being completed. MB moved to a residential care setting, the capacity assessment indicated she had capacity to make the decision to move. The advocate and Sage legal advisor visited MB to discuss the next steps, MB requested Sage to tell the Court she did not want to be made a ward of court and informed Sage of her understanding of the NHSS and Ancillary State Loan to pay for care. Sage assisted her to complete an enquiry form to challenge the wardship application. A copy of the formal capacity assessment which determined MB had capacity to decide to go to residential care, an independent capacity assessment was submitted to the President of the High Court by Sage on behalf of MB. Sage stated its role in court was to have MB's voice heard in the context of an advocacy service for MB and was not acting on behalf of MB. The Court subsequently permitted Sage to be heard in Court as Sage's legal advisor is an officer of the Court. The President determined there was a clash of medical evidence in relation to capacity, and ordered an exchange of evidence. Sage met with MB to update her and discuss next steps. Sage explained that the Court may not permit Sage to speak for her. MB said she did not want a solicitor and asked Sage to try to represent her. An authority to act form signed by MB was handed to the President who accepted it as a request of an enquiry and allowed Sage legal advisor to be heard in that capacity "de bene esse", that is, he would deal with the entitlement of Sage to represent MB in his judgement. The capacity assessment submitted by Sage was disputed by the applicant. The capacity assessment submitted

by the applicant made a determination on MB's 'unsoundness of mind' on her insight into her care needs, and used this determination as an indication of lack of capacity to make financial and other decisions, although he stated he didn't specifically assess capacity for these decisions as in his view one deficit meant there were other deficits. A request for the Sage legal advisor to give evidence to the court was challenged by the HSE. Following consideration by the President the wardship application was granted and MB became a ward of court. Sage was informed that its right of audience as an advocacy service would not be allowed in other cases. [Sage Annual Report Case example 5<sup>128</sup>]

## C. HIQA Inspection Reports and Notifications

### Record of individual concerns and allegations of abuse made to the Health Information and Quality Authority (HIQA).

*HIQA does not have a remit to respond to individual concerns/complaints, HIQA records concerns received and information is used to inform monitoring role. Records from 3<sup>rd</sup> November 2015 to 5<sup>th</sup> March 2016 and 20<sup>th</sup> July to 1<sup>st</sup> November 2016 were released under Freedom of Information requests to The Journal.ie with details redacted, record below text in quotations is from the HIQA records.*

- Person was "discovered... lying on the bedroom floor covered in urine and faeces"; no "apparent protocol or system for the prevention of falls". The complainant also states that "food at the care facility is badly prepared and cooked".
- Person's room described as "like a prison cell"
- Person's "incontinence wear is not changed regularly" and "no systems in place to prevent the spread of infection".
- Person was "sitting on the toilet seat" for a number of hours.
- Person had experienced "emotional and physical bullying".
- Persons at a centre "were refused water due to the risk of them getting wet..."
- Person found [X] sitting in wet underwear on several occasions and that states that "no dignity or respect is shown" to them.
- Staff "no longer encourages [X] to get out of bed"; person is "left sitting in wet underwear".
- Concerns of alleged abuse against elderly patients, with staff using aggressive behaviour and being verbally abusive; dehydration due to a lack of water; an allegation of sexual assault; cleanliness of care centres; most common concerns related to understaffing and inadequate training of staff.

### HIQA Inspection Reports under Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2013

- In 2016 an inspection report of a residential care setting for older people showed that chemical restraint was used with two residents to manage their behaviours, and the incidents had not been notified as required to HIQA; and two incidents of money going missing from residents' rooms were logged as complaints, and not financial abuse, there were no records of an investigation held by the provider, and the incident was not notified to HIQA.<sup>129</sup>
- In 2016 an inspection report of a residential care setting for older people highlighted ongoing concerns of lack of storage space, accommodation in communal bedrooms,

inaccessible shower and toilet facilities, although screens were being used there was a poor level of privacy when equipment is being used.<sup>130</sup>

- In 2017 HIQA sought an order to cease admissions to a HSE residential care setting for long stay and short stay residents based on the quality of life of residents. Residents and relatives feedback was included in the Inspection Report, and were supported by the inspection findings.<sup>131</sup> Residents stated they “had nothing to do”, concerns of staff levels impact on personal hygiene routine, and having to wait for long periods for staff. HIQA found premises did not meet privacy and personal space needs, or have adequate dining and communal space and accessible sanitary facilities.<sup>132</sup> The order was challenged by the HSE, in Court HIQA inspectors noted that some residents were in bed from 4.30pm until 8.00am, were institutionalised due to the culture of the centre with a routine of getting up, sitting by their bed all day and going to bed at 4.30pm, and a resident who was afraid to leave her bed as she was afraid it would be gone. In response HSE stated there are no other options in the area for short stay residents if the centre was closed, redevelopment plans for the centre would be complete in 2021.<sup>133</sup>

### **HIQA Inspection Reports under Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013**

It has been noted by HIQA that regulations of designated centres for persons with disabilities which commenced in 2013, is improving the lives of people with disabilities living under the care of the State<sup>134</sup> there are a number of serious concerns around abuse and mistreatment within institutional settings.

- In 2016 HIQA issued a notice to cancel and refuse registration of three residential centres for people with autism run by the Irish Society for Autism, as there was not sufficient improvement in the standard of care following inspections. Concerns related inadequate safeguarding measures to protect residents from assault, inappropriate guidance on the use of chemical restraint, and poor governance and oversight by the provider. As there was not sufficient improvement following inspections, the three centres were taken into the direct charge of the HSE.<sup>135</sup>
- In 2016 HIQA’s noted concerns about four large congregated settings provided by the HSE due to significant issues in relation to safeguarding of residents from abuse, and management were not effective in ensuring the rights of residents were protected and promoted.<sup>136</sup>
- In 2017 HIQA cancelled the registration of a residential centre and direct charge was transferred to the HSE, due to ongoing and significant failings by the provider to safeguard residents from abuse, including potentially abusive incidents of intimate care and physical restraint, and allegations of serious physical and sexual abuse.<sup>137</sup>

## 8. References and Citations

<sup>1</sup> Sage Support & Advocacy Service was funded by the HSE and Atlantic Philanthropies with the support and governance of Third Age CLG.

<sup>2</sup> On 20<sup>th</sup> May 2005 RTE Prime Time broadcast *'Home Truths'* a documentary featuring footage filmed inside Leas Cross Nursing Home, Co. Dublin. The programme highlighted serious deficiencies in the treatment and care of people in Leas Cross and led to the establishment of a Commission of Investigation to increase understanding of what happened in Leas Cross, why it happened and reasons why it was allowed to happen. <http://health.gov.ie/wp-content/uploads/2014/03/leascross.pdf> A review of deaths that occurred at Leas Cross was carried out, and found deficient care, insufficient trained staff, lack of recognition by management and clinical leadership of the care needs of people in the home, and a finding of institutional abuse. ( O'Neill, D. 2006. *Leas Cross Review*. Available at [http://www.hse.ie/eng/services/publications/olderpeople/Leas\\_Cross\\_Report\\_.pdf](http://www.hse.ie/eng/services/publications/olderpeople/Leas_Cross_Report_.pdf) [accessed 21/06/2017]. The findings and recommendations regarding Leas Cross led to the establishment of the Health Information and Quality Authority (HIQA) in 2009.

<sup>3</sup> See Appendix 7A.

<sup>4</sup> Second Periodic Report of Ireland to CAT 23 November 2015, (CAT/C/IRL/2)

<sup>5</sup> *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Mendéz (A/HRC/22/53 at 1<sup>st</sup> February 2013)*, at para 15, p. 4. available at [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf) [accessed 14/06/2016]

<sup>6</sup> Ibid, para 82, p. 20

<sup>7</sup> Ibid, para 50, "Patients in health-care settings are reliant on health-care workers who provide them services. As the previous Special Rapporteur stated: "Torture, as the most serious violation of the human right to personal integrity and dignity, presupposes a situation of powerlessness, whereby the victim is under the total control of another person." Deprivation of legal capacity, when a person's exercise of decision-making is taken away and given to others, is one such circumstance, along with deprivation of liberty in prisons or other places."

<sup>8</sup> Central Statistics Office (2013). *Population and Labour Force Projections 2016-2046*. Dublin: Government of Ireland

[http://www.cso.ie/en/media/csoie/releasespublications/documents/population/2013/poplabfor2016\\_2046.pdf](http://www.cso.ie/en/media/csoie/releasespublications/documents/population/2013/poplabfor2016_2046.pdf) [accessed 08/06/2017]

<sup>9</sup> Donnelly, S., O'Brien, M., Begley, E. and Brennan, J. (2016). *"I'd prefer to stay at home but I don't have a choice" Meeting Older People's Preference for Care: Policy, but what about practice?* Dublin: University College Dublin. Available at

[http://www.dementia-neurodegeneration.ie/sites/default/files/publications/staying\\_at\\_home\\_-\\_older\\_peoples\\_preference\\_for\\_care\\_2016.pdf](http://www.dementia-neurodegeneration.ie/sites/default/files/publications/staying_at_home_-_older_peoples_preference_for_care_2016.pdf) [accessed 23/06/2017]

<sup>10</sup> Sage Support & Advocacy Service for Older People (2016), *Responding to the Support & Care Needs of our Older Population*,

[http://www.thirdageireland.ie/assets/site/files/pr/Report\\_of\\_Forum\\_on\\_LTC\\_for\\_Older\\_People\\_FINAL.pdf](http://www.thirdageireland.ie/assets/site/files/pr/Report_of_Forum_on_LTC_for_Older_People_FINAL.pdf) [accessed 08/06/2017]

<sup>11</sup> The Health Information and Quality Authority is an independent authority established under the Health Act 2007 (<http://www.irishstatutebook.ie/eli/2007/act/23/enacted/en/pdf>) to drive high-quality and safe care for people using our health and social care services in Ireland. HIQA's mandate to date extends across a specified range of public, private and voluntary sector services. Reporting to the Minister for Health and the Minister for Children and Youth Affairs, HIQA's role is to develop standards, inspect and review health and social care services and support informed decisions on how services are delivered. The regulation of services operates under National Standards, legislation and regulation. Of particular relevant to this report HIQA inspects residential care centres against *National Standards for Residential Care Settings for Older People (2016)* <https://www.hiqa.ie/sites/default/files/2017-01/National-Standards-for-Older-People.pdf> and *National Standards for Residential Services for Children and Adults (2013)* <https://www.hiqa.ie/sites/default/files/2017-02/Standards-Disabilities-Children-Adults.pdf>

<sup>12</sup> Sage Support and Advocacy Service (2016) *The Nursing Home Support Scheme – Charges and Related Issues* Discussion Paper available at

[http://www.thirdageireland.ie/assets/site/files/pr/Discussion\\_doc\\_Nursing\\_Home\\_Charges.pdf](http://www.thirdageireland.ie/assets/site/files/pr/Discussion_doc_Nursing_Home_Charges.pdf) [accessed 22/06/2017, page 4]

- <sup>13</sup> See presentation by Deirdre Cullen, Central Statistics Office (CSO) delivered to The Citizens' Assembly on 10<sup>th</sup> June 2017, available at <https://www.citizensassembly.ie/en/Meetings/Deirdre-Cullen.pdf> [accessed 26/06/2017]
- <sup>14</sup> Health Information and Quality Authority 2017, *Overview of 2016 HIQA regulation of social care and healthcare services*. Dublin, HIQA <https://www.hiqa.ie/sites/default/files/2017-04/Regulation-overview-2016-web.pdf> .[accessed 09/06/2017]
- <sup>15</sup> Government of Ireland, 2017. *Census 2016 Summary Results – Part 2*. Dublin: Central Statistics Office. Available from [http://www.cso.ie/en/media/csoie/newsevents/documents/census2016summaryresultspart2/Census\\_2016\\_Summary\\_Results\\_%E2%80%93\\_Part\\_2.pdf](http://www.cso.ie/en/media/csoie/newsevents/documents/census2016summaryresultspart2/Census_2016_Summary_Results_%E2%80%93_Part_2.pdf) [accessed 15/06/2017]
- <sup>16</sup> See <http://www.disability-federation.ie/index.php?uniqueID=10598> [accessed 14/06/2017]
- <sup>17</sup> "One-third of in-patients on census night were aged 65 years and over; 17% were aged 55–64 years; a further 17% were aged 45–54 years; 15% were aged 35–44 years; 12% were aged 25–34 years; and 5% were under 25 years of age. The 75-year and over age group, which accounted for 17% of all residents, had the highest hospitalisation rate, at 180.4 per 100,000 population, followed by the 65–74 year age group, at 125.3..." "Half of those who had been hospitalised for five years or more on census night were aged 65 years and over. Thirty-six per cent (36.5%) of those who were aged 75 years or over had been in hospital for five years or more on census night." Health Research Board, 2013 *Irish Psychiatric Units and Hospitals Census Bulletin November 2013* from [http://www.hrb.ie/uploads/tx\\_hrbpublications/IrishPsychiatricUnitsandHospitalsCensusBulletin\\_2013.pdf](http://www.hrb.ie/uploads/tx_hrbpublications/IrishPsychiatricUnitsandHospitalsCensusBulletin_2013.pdf) [accessed 14/06/2017]
- <sup>18</sup> <http://www.hse.ie/eng/services/list/4/olderpeople/dementia/about-dementia/>
- <sup>19</sup> Pierse, M., Cahill, S., O'Shea, E. 2014 *Prevalence and Projections of Dementia in Ireland, 2011 – 2046*. Dublin: Genio [https://www.genio.ie/system/files/publications/Dementia\\_Prevalence\\_2011\\_2046.pdf](https://www.genio.ie/system/files/publications/Dementia_Prevalence_2011_2046.pdf) [accessed 14/06/2017]
- <sup>20</sup> Cahill, S., O'Nolan, C., O'Cahey, D. & Bobersky, A., 2013. *An Irish National Survey of Dementia in Long-Term Residential Care*. Dublin: Dementia Services Information and Development Centre available from [http://dementia.ie/images/uploads/site-images/DSIDCSCURReport\\_439721.pdf](http://dementia.ie/images/uploads/site-images/DSIDCSCURReport_439721.pdf) [accessed 14/06/2017]
- <sup>21</sup> Health Service Executive, 2014. *Safeguarding Vulnerable Persons at Risk of Abuse National Policy and Procedures*. Available at <http://www.hse.ie/eng/services/publications/corporate/personsatriskofabuse.pdf> [accessed 18/06/2017],
- <sup>22</sup> HSE National Safeguarding Office, 2017. *2016 Safeguarding Data Report*. <http://www.hse.ie/eng/services/publications/olderpeople/Safeguarding-Data-Report-2016.pdf> [accessed 18/06/2017]
- <sup>23</sup> Health Information and Quality Authority, 2016. *Annual overview report on the regulation of designated centres for older people – 2015*. Available at <https://www.hiqa.ie/sites/default/files/2017-02/2016-Overview-Centres-Older-People.pdf> [accessed 18/06/2017]; Ryan, O. (14<sup>th</sup> April 2016) "There should be national outrage: 20% rise in reports of abuse in elderly care homes", *The Journal* available at <http://www.thejournal.ie/rise-abuse-nursing-homes-hiqa-2715336-Apr2016/> [accessed 17/06/2017]
- <sup>24</sup> Health Information and Quality Authority, 2016. *Annual overview report on the regulation of designated centres for adults and children with disabilities – 2015*. Available at [https://www.hiqa.ie/sites/default/files/2017-01/Disability\\_Overview\\_Report\\_2015.pdf](https://www.hiqa.ie/sites/default/files/2017-01/Disability_Overview_Report_2015.pdf) [accessed 18/06/2017]
- <sup>25</sup> The Confidential Recipient was appointed in December 2014 to be a voice for vulnerable adults who may otherwise not be heard by the HSE or providers funded / partially funded by the HSE. The role was appointed as part of the State's response to abuse of residents by staff in Áras Attracta, a residential home for people with disabilities. The Confidential Recipient receives complaints/concerns independently, and passes these to the HSE Chief Officer who has 15 days to respond to the Confidential Recipient in relation to the concern.
- <sup>26</sup> Confidential Recipient, 2017. *Report of the Confidential Recipient 2016*. Available at <http://www.hse.ie/eng/services/publications/corporate/Report-of-the-Confidential-Recipient-2016.pdf> [accessed 18/06/2017]
- <sup>27</sup> REDC, 2017. *Vulnerable Adults in Irish Society- Nationwide Public Opinion Survey*. Available at <http://safeguardingcommittee.ie/wp-content/uploads/2017/04/Red-C-Survey-Vulnerable-Adults-in-Irish-Society-060417.pdf> [accessed 21/06/2017]
- <sup>28</sup> *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez (A/HRC/22/53 at 1<sup>st</sup> February 2013)*, at para 65, p. 15. available at

[http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf)  
[accessed 14/06/2016]

<sup>29</sup> Assisted Decision-Making (Capacity) Act 2015

<http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html>

<sup>30</sup> Accurate at the time of writing. The State has indicated that commencement of the ADM (Capacity) Act 2015 will be on a phased basis, in response to a Parliamentary Question on commencement on 29<sup>th</sup> November 2016 the Tánaiste and then Minister for Justice and Equality stated that "...it is my intention that the new decision-making support options provided for in the Act will be substantially implemented during 2017."

(<https://www.kildarestreet.com/wrans/?id=2016-11-29a.160>, accessed 16/06/2017).

To date two commencement orders have been signed, one to enable the recruitment of a Director of the Decision Support Service (Assisted Decision-Making (Capacity) Act 2015 (Commencement of Certain Provisions) Order 2016 (S.I. No. 515 of 2016) and one to enable the establishment of a multi-disciplinary group to develop codes of practice on advance healthcare directives (Assisted Decision-Making (Capacity) Act 2015 (Commencement of Certain Provisions) (No. 2) Order 2016 (S.I. No. 517 of 2016). The position for Director of the Decision Support Service (DSS) and a DSS Project Manager were advertised in 2017.

<sup>31</sup> Lunacy Regulation (Ireland) Act, 1871 <http://www.irishstatutebook.ie/eli/1871/act/22/enacted/en/html>

<sup>32</sup> UN General Assembly, *Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly*, 24 January 2007, A/RES/61/106, available at:

<http://www.refworld.org/docid/45f973632.html> [accessed 26/06/2017]

<sup>33</sup> Courts Service, 2003. *Office of Wards of Court - an information booklet*. Available from

[http://www.courts.ie/Courts.ie/library3.nsf/\(WebFiles\)/E6C1CF1ED06088A1802579050051CD90/%24FILE/War ds%20of%20court%20booklet.pdf](http://www.courts.ie/Courts.ie/library3.nsf/(WebFiles)/E6C1CF1ED06088A1802579050051CD90/%24FILE/War ds%20of%20court%20booklet.pdf) [accessed 15/06/2017]

<sup>34</sup> Reilly, J. (21<sup>st</sup> February 2016) "Dementia Cases in Limbo for up to eight months" *Irish Independent* available at <http://www.independent.ie/irish-news/health/dementia-cases-in-limbo-for-up-to-eight-months-34471286.html>

<sup>35</sup> Cullen, P. (18 January 2017) "Elderly being left in hospital beds to 'shelter family inheritance'", *Irish Times* available at <http://www.irishtimes.com/news/health/elderly-being-left-in-hospital-beds-to-shelter-family-inheritance-1.2940695>

<sup>36</sup> State supported long-term residential care is provided under the Nursing Home Support Scheme (NHSS) which has a statutory basis, Nursing Home Support Scheme Act 2009,

<http://www.irishstatutebook.ie/eli/2009/act/15/enacted/en/pdf> [accessed 21/06/2017]

Under the NHSS, all entrants into long term residential care, both public and private/voluntary, are subject to a care needs and means assessment. The scheme makes available two types of financial support: State Support & Ancillary State Support (Nursing Home Loan). People are assessed financially based on both income and assets. Individuals contribute up to 80% of their assessable income and 7.5% of the value of their assets per annum, up to maximum of three years.<sup>36</sup> An application for the NHSS can be submitted by specified people on behalf of a person in certain circumstances. The principal residence is considered as part of their assets for the first 3 years only. Where an individual's assets include land and property in the State, the contribution based on these assets may be deferred and collected from their estate after their death. This is the optional nursing home loan element of the scheme, legally referred to as Ancillary State support. This creates a financial charge to be collected from the estate of the person. There are a number of safeguards built into the NHSS to protect both the person entering a nursing home and his/her spouse/partner. These include: Nobody paying more than the actual cost of care; The first €36,000 for a person's assets (€72,000 for a couple) not taken into account during the financial assessment; The principal residence (and farms/businesses in certain circumstances) only included in the financial assessment for the first three years of a person's time in care; Individuals retaining a personal allowance of 20% of their income, or 20% of the maximum rate of the State Pension (Non-Contributory), whichever is the greater; A spouse/partner remaining at home retaining 50% of the couple's income, or the maximum rate of the State Pension (Non-Contributory), whichever is the greater; Certain items of expenditure, 'allowable deductions,' taken into account during the financial assessment – health expenses, levies required by law (e.g., Local Property Tax), rent payments and borrowings in respect of a person's principal residence. The process of applying for the NHSS scheme on behalf of a person whose capacity is in question or has been determined to lack capacity utilises a process of a court appointed Care Representative for the sole purpose of applying for an Ancillary State Support loan on a person's property (Nursing Home Support Scheme Act 2009, Section 21) to pay for costs of care on behalf of a person whose has

reduced capacity and “wishes to apply for the Nursing Home Loan.”

<http://www.hse.ie/eng/services/list/4/olderpeople/nhss/NHSS%20Information%20Booklet.pdf> The Care Representative role, commonly granted to a person’s next of kin, does not give any other legal authority to make decisions on behalf of the person (*Responding to the Support & Care Needs of our Older Population*, page 29)

<sup>37</sup> As reported in the *Irish Times* newspaper, documents sought under Freedom of Information requests following the leak of a controversial memo pointed to practices of seeking wardship in the removal of patients from acute hospital beds who no longer required acute care. The HSE Head of Legal Services was reported as saying “...she had received ‘very many queries’ from hospitals on dealing with such issues. In the Midlands, she noted, the HSE makes a significant number of applications for wardship for patients who are in beds they no longer require. ‘The same pattern is not evident to the same extent elsewhere.’” Cullen, P. (18 January 2017) “Elderly being left in hospital beds to ‘shelter family inheritance’”, *Irish Times* available at <http://www.irishtimes.com/news/health/elderly-being-left-in-hospital-beds-to-shelter-family-inheritance-1.2940695>

<sup>38</sup> Sage Support and Advocacy Service, 2017. *Annual Report 2016*. [to be launched on 26/07/2017, available from <http://sageadvocacy.ie/index.php/resources-1/>]

<sup>39</sup> In the Northern Ireland Human Rights Commission Report *In Defence of Dignity – The Human Rights of Older People in Nursing Homes* the jurisprudence of the European Court of Human Rights is examined in relation to the prohibition on torture and inhuman or degrading treatment under Article 3 of the ECHR (Council of Europe, *European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14*, 4 November 1950, ETS 5, available at:

<http://www.refworld.org/docid/3ae6b3b04.html> [accessed 26 June 2017]) it states that ‘...in the context of degrading treatment the Court has held that it may well suffice that the victim is humiliated in his or her own eyes, even if not in the eyes of others.’ *Costello-Roberts v UK* (25 March 1993) Application No 13134/87 as in Northern Ireland Human Rights Commission, 2012. *In Defence of Dignity – The Human Rights of Older People in Nursing Homes*. Page 22 Available from <http://www.nihrc.org/documents/research-and-investigations/older-people/in-defence-of-dignity-investigation-report-March-2012.pdf> [accessed 15/06/2017]. The report offers analysis of how neglect, debasement and humiliation of a person can be considered to violate the absolute right to not be subjected to torture, or to inhuman or degrading treatment or punishment.

<sup>40</sup> Assisted Decision-Making (Capacity) Act 2015, Ibid 29, Section 3(1).

<sup>41</sup> Assisted Decision-Making (Capacity) Act 2015, Ibid 29, Section 55.

<sup>42</sup> Disability (Miscellaneous Provisions) Bill 2016,

<https://www.oireachtas.ie/documents/bills28/bills/2016/11916/b11916d.pdf>

<sup>43</sup> *Disability (Miscellaneous Provisions) Bill 2016: Explanatory Memorandum*, page 2 available at <https://www.oireachtas.ie/documents/bills28/bills/2016/11916/b11916d-memo.pdf>

<sup>44</sup> Deputy Finian McGrath *Dáil Éireann Debates Vol. 940 No. 2*, 23<sup>rd</sup> February 2016, available

[http://oireachtasdebates.oireachtas.ie/debates%20authoring/debateswebpack.nsf/\(indexlookupdail\)/20170223~Y?opendocument#Y00600](http://oireachtasdebates.oireachtas.ie/debates%20authoring/debateswebpack.nsf/(indexlookupdail)/20170223~Y?opendocument#Y00600)

<sup>45</sup> Irish Human Rights and Equality Commission, 2017. *Submission to the Citizens’ Assembly in its consideration of ‘How we respond to the challenges and opportunities of an ageing population’* available <https://www.ihrec.ie/app/uploads/2017/05/Submission-to-the-Citizens-Assembly-in-its-consideration-of-How-we-respond-to-the-challenges-and-opportunities-of-an-ageing-population-19-May-2017-003.pdf> [accessed 16/06/2017]

<sup>46</sup> Mental Health Act 2011, available at <http://www.irishstatutebook.ie/eli/2001/act/25/enacted/en/pdf>

<sup>47</sup> 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.

<sup>48</sup> Donnelly, S. et al. Ibid 9

<sup>49</sup> *Sage Annual Report 2016* Ibid 38, page 29

<sup>50</sup> “...at the time of the visit, St Joseph’s Disability Services did not accommodate any resident detained under the 2001 Mental Health Act and, with the exception of 13 “wards of Court”, all residents had been voluntarily admitted. However, many of these so-called voluntary residents were de facto detained: they lived in a closed unit and were not allowed to leave the institution without prior permission”. Page 79 [https://www.childrensrighs.ie/sites/default/files/submissions\\_reports/files/CPT-VisitingCommitteeIrelandReport2011\\_0.pdf](https://www.childrensrighs.ie/sites/default/files/submissions_reports/files/CPT-VisitingCommitteeIrelandReport2011_0.pdf)

<sup>51</sup> Newstalk Breakfast (14<sup>th</sup> December 2016) *The Independent Lives of the Elderly in Ireland* available at [http://www.newstalk.com/podcasts/Newstalk Breakfast/Highlights from Newstalk Breakfast/171109/The independent lives of the elderly in Ireland](http://www.newstalk.com/podcasts/Newstalk%20Breakfast/Highlights%20from%20Newstalk%20Breakfast/171109/The%20independent%20lives%20of%20the%20elderly%20in%20Ireland) [accessed 22/06/2017].

<sup>52</sup> “Antipsychotic medications increase mortality and cause strokes, among other problems. While such medications have a role in treating distress caused by problems such as psychosis, it is a consistent finding that approximately 50% of use in nursing homes is for inappropriate indications, often to ensure the smooth running of the institution or to lessen disruption for others (Murphy and O’Keeffe, 2007).” *Murphy, J. and O’Keeffe, S.T. (2008) ‘Frequency and appropriateness of antipsychotic medication use in older people in long-term care’, Irish Journal of Medical Science, 177(1): 35 as in O’Keeffe, S. 2016. ‘Legal and Ethical Considerations in Involuntary Admissions to Long-term Care’ as in Donnelly, M. & Murray, C. (Eds.), 2016. Ethical and Legal Debates in Irish Healthcare: Confronting Complexities* England: Manchester University Press, Page 128

<sup>53</sup> Department of Health, 2009. *Towards a Restraint Free Environment in Nursing Homes*, page 2, available at [http://health.gov.ie/wp-content/uploads/2014/03/trfe\\_english.pdf](http://health.gov.ie/wp-content/uploads/2014/03/trfe_english.pdf) [accessed 23/06/2017]

<sup>54</sup> HIQA, 2014. *Guidance for Designated Centres Restraint Procedures*, page 4 available at <https://www.hiqa.ie/sites/default/files/2017-01/Guidance-on-restraint-procedures.pdf> [accessed 23/06/2017]

<sup>55</sup> The Medical Council has responsibility for the regulation of medical doctors, ensuring standards of medical training and education, promoting good medical practice and investigating complaints about medical doctors.

<sup>56</sup> Medical Council, 2016. *Guide to Professional Conduct and Ethics for Registered Medical Practitioners 8<sup>th</sup> Edition 2016*, page 36, available at <https://www.medicalcouncil.ie/News-and-Publications/Reports/Guide-to-Professional-Conduct-and-Ethics-8th-Edition-2016-.pdf> [accessed 23/06/2017]

<sup>57</sup> Sage Support and Advocacy Service (28<sup>th</sup> July 2016) “Older people being sedated for ‘convenience’, senior consultant warns”, Press Statement, available at <http://www.thirdageireland.ie/sage/latest-news/press-releases/older-people-being-sedated-for-convenience-senior-consultant-warns>

<sup>58</sup> Sage Support and Advocacy Service for Older People letter from Mervyn Taylor, Sage Manager to Minister Kathleen Lynch, 3<sup>rd</sup> November 2015.

<sup>59</sup> HIQA, 2017, *Overview of 2016 HIQA regulation of social care and healthcare services*, Ibid 14, page 31

<sup>60</sup> Sage Support and Advocacy Service, 2016, Ibid 10; Donnelly, S. et al (2016), Ibid 9.

<sup>61</sup> Donnelly, S. et al (2016), Ibid 9, page 17

<sup>62</sup> State supported community care is provided for through the provision of Home Care Packages Scheme and Home Help which are implemented by the Health Service Executive (HSE). The emphasis in health care policy relating to ageing and health care since the late 1960s has been on enabling older persons to live in their homes for as long as possible (*Working Party on Services for the Elderly, 1988. The Years Ahead: A Policy for the Elderly. Dublin: Stationery Office*). However, to date, no statutory obligation exists to compel the State to provide community based services to everyone. “Home Care Packages (HCPs), first introduced in 2006, are the main current community care policy fulcrum. These are packages of care tailored to the needs of individuals whose needs cannot be met by mainstream Primary, Community and Continuing Care (PCCC) services. The overall objective of HCPs is to maintain older people at home and in their communities, particularly those at risk of inappropriate admission to long-term care or acute hospitals. HCPs provide a broader range of supports than home helps and can include some therapy and nursing support for a few weeks after a hospital stay to ongoing, daily visits from a home care assistant to help a person get out of bed, washed and dressed. They can include a range of services, such as public health nursing, day care, occupational therapy, physiotherapy, home help, home care and respite care, that are shaped around each person’s individual needs. HCPs can either be provided through a cash grant, which the recipient can use to purchase the care and support they need or through the organisation of care services by the HSE.” (*Responding to the Support & Care Needs of our Older Population*, Ibid 10, page 25); “National Guidelines and Procedures for Standardised Implementation of the Home Care Packages Scheme were published in 2010 [HSE, available at <http://lenus.ie/hse/bitstream/10147/120850/1/hcpsguidelines.pdf>] These guidelines and procedures noted that the extent of the support available through the Home Care Package Scheme is subject to the limit of the

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resources allocated each year to the HSE for the running of the scheme.”

(*Responding to the Support & Care Needs of our Older Population*, Ibid 10, page 26)

<sup>63</sup> Donnelly, S. et al (2016), Ibid 9

<sup>64</sup> Wren et. Al (2012) *Towards the Development of a Predictive Model of Long-Term Care Demand For Northern Ireland and the Republic of Ireland* available at [http://www.cardi.ie/userfiles/CARDI\\_final%20print\\_231012.pdf](http://www.cardi.ie/userfiles/CARDI_final%20print_231012.pdf) [accessed 23/06/2017]; Sage Support & Advocacy Service for Older People (2016), *Responding to the Support & Care Needs of our Older Population*, [http://www.thirdageireland.ie/assets/site/files/pr/Report\\_of\\_Forum\\_on\\_LTC\\_for\\_Older\\_People\\_FINAL.pdf](http://www.thirdageireland.ie/assets/site/files/pr/Report_of_Forum_on_LTC_for_Older_People_FINAL.pdf) [accessed 08/06/2017]; Sage Support & Advocacy Service (2017) *A Submission to the Citizens Assembly* available at

[http://www.thirdageireland.ie/assets/site/files/pr/Sage\\_Submission\\_to\\_Citizens\\_Assembly\\_050517\\_%28002%29.pdf](http://www.thirdageireland.ie/assets/site/files/pr/Sage_Submission_to_Citizens_Assembly_050517_%28002%29.pdf) [accessed 23/06/2017];

<sup>65</sup> Finance Act (1998) <http://www.irishstatutebook.ie/eli/1998/act/3/enacted/en/pdf>; O'Halloran, B. (19<sup>th</sup> July 2005) "Tax breaks turn nursing homes into big money-spinners", *Irish Times* available at <https://www.irishtimes.com/news/health/tax-breaks-turn-nursing-homes-into-big-money-spinners-1.470129> [accessed 23/06/2017]

<sup>66</sup> The Health Service Executive (HSE) Service Plan, 2017, [HSE, 2017. *National Service Plan 2017*,, available at <http://www.hse.ie/eng/services/publications/serviceplans/Service-Plan-2017/2017-National-Service-Plan.pdf>) provides for an additional €18.5 million on 2016 rate for the Nursing Home Support Scheme, allowing an additional 490 people to be funded in long term residential care which increases the funding to cater for over 23,600 people in long-term residential care. This compares to an additional €10 million for Home Care funding, which results in no increase on allocation of 10.570 million hour of Home Help hours, but an additional 300 Home Care Packages giving a capacity to provide a package to 16,750 people.

<sup>67</sup> Sage Support & Advocacy Service. 2017. *A Submission to the Citizens Assembly* available at [http://www.thirdageireland.ie/assets/site/files/pr/Sage\\_Submission\\_to\\_Citizens\\_Assembly\\_050517\\_%28002%29.pdf](http://www.thirdageireland.ie/assets/site/files/pr/Sage_Submission_to_Citizens_Assembly_050517_%28002%29.pdf) [accessed 23/06/2017];

<sup>68</sup> Sage recently highlighted a case of *de facto* detention in its work as a support and advocacy case, stating on behalf of a person that he felt "...his human rights were violated by being kept against his will in the nursing home and equally he feels he has the right to decide on his own future even if this involves risk or is seen by others as being unsafe.”

<sup>69</sup> HSE, 2011. *Time to Move on from Congregated Settings - A Strategy for Community Inclusion*, available at <http://www.hse.ie/eng/services/list/4/disability/congregatedsettings/congregatedsettingsreportfinal.pdf> [accessed 23/06/2017]; Department of the Environment, Community & Local Government, 2011. *National Housing Strategy for People with a Disability 2011 – 2016*, available at <https://www.housingagency.ie/Housing/media/Media/Disability%20Strategy/National-Implementation-Framework-2012.pdf> [accessed 23/06/2017]; HSE, 2012. *New directions – review of HSE day services and implementation plan 2012–2016*, available at

<http://www.hse.ie/eng/services/publications/Disability/newdirections2012.pdf> [accessed 23/06/2017]; Department of Health, 2012. *Transforming Lives: Programme to implement the Value for Money and Policy Review of Disability Services in Ireland* [http://health.gov.ie/wp-content/uploads/2014/03/VFM\\_Disability\\_Services\\_Programme\\_2012.pdf](http://health.gov.ie/wp-content/uploads/2014/03/VFM_Disability_Services_Programme_2012.pdf) [accessed 23/06/2017]

<sup>70</sup> In December 2016, there were 436 recorded delayed discharges from acute hospital, reflecting 436 people who are medically ready for discharge but unable to do so as they do not have an appropriate place to go. 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 26<sup>th</sup> May 2007 [http://www.irishgerontology.com/sites/default/files/basic\\_page\\_pdf/M.%20Fitzgerald%2C%20Services%20for%20Older%20People%2C%20HSE.pdf](http://www.irishgerontology.com/sites/default/files/basic_page_pdf/M.%20Fitzgerald%2C%20Services%20for%20Older%20People%2C%20HSE.pdf) [accessed 09/06/2017]

<sup>72</sup> Delayed discharges were estimated to cost the State €540,000 per night based on research in 2013 when there were 685 people in acute hospital whose acute care needs had ended, the cost of a hospital bed per night was between €800-900. Delays were due to people waiting for nursing home care, home help or rehab facilities and equipment. (HCCI, 2013 <http://www.hcci.ie/2013-08.html>; Ring, E. (29<sup>th</sup> 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>

<sup>73</sup> "From the CPT's standards and developing jurisprudence, it is clear that inhuman and degrading treatment can relate to everyday living conditions, the availability of therapeutic activity, eating arrangements, staffing levels, training and the use of restraint. The CPT's standards are often developed in the specific context of psychiatric units and social care homes where people are involuntarily detained. While the CPT has not been explicit on how it would assess the conditions in a home in which residents are not, and are not likely to be, detained under the provisions of domestic law, the standards serve as useful guidance on an institution's treatment of any person with cognitive impairments or fluctuating capacity. Residents in nursing homes with dementia would come under this category. Indeed, although the Committee's visits have traditionally focused on criminal justice establishments and psychiatric facilities, they have included residential and nursing homes for older people since 2000". Extract from Northern Ireland Human Rights Commission, 2012. *In Defence of Dignity – The Human Rights of Older People in Nursing Homes*. Page 18. Available from <http://www.nihrc.org/documents/research-and-investigations/older-people/in-defence-of-dignity-investigation-report-March-2012.pdf> [accessed 15/06/2017].

<sup>74</sup> *Sage Annual Report*, Ibid 38

<sup>75</sup> A public opinion survey that showed 1) Being cared for in their own home is the most preferred option for respondents if they should ever need long term care 2) In terms of funding long term care, the greatest overall preference is through general taxation. 3) There is greater preference for public provision of long term care for older people, considerable support for social enterprise and least support for provision through the private sector. Amárach Research (2016) as in Sage Support & Advocacy Service for Older People, 2016, Ibid 10.

<sup>76</sup> Sage Support & Advocacy Service for Older People, 2016, Ibid 10 & HIQA (2017) *Executive Summary: Exploring the regulation of health and social care services. Disability and Older People's services*. <https://www.hiqa.ie/sites/default/files/2017-05/exec-summary-exploring-the-regulation-of-health-and-social-care.pdf> [accessed 11/06/2018] Page 3

<sup>77</sup> Chair of the National Safeguarding Committee, Patricia Rickard-Clarke statement on the launch of a public information campaign launched to improve safeguarding of vulnerable adults. Available at <http://safeguardingcommittee.ie/index.php/2017/06/12/almost-8000-cases-of-adult-abuse-concerns-reported-to-hse/> [accessed 18/06/2017]

<sup>78</sup> IHREC, 2017. Ibid 45

<sup>79</sup> "HIQA believes that the area of safeguarding needs to be further strengthened by introducing legislation which would enshrine adult safeguarding in law and acknowledge the State's responsibility to protect those who may be at risk..... The introduction of such legislation would enhance the suite of other legislation aimed at promoting and protecting the rights of people who may be vulnerable." Health Information and Quality Authority, 2017. *Overview of 2016 HIQA regulation of social care and healthcare services*. Dublin, HIQA <https://www.hiqa.ie/sites/default/files/2017-04/Regulation-overview-2016-web.pdf> [accessed 09/10/2017], Page 7

<sup>80</sup> Commenting on the process of decongregation of people with disabilities from institutional care settings HIQA noted "...some residents are moving to living arrangements that are not subject to regulatory oversight and these residents do not have the same legal protections as those protections provided to residents who live or had been living beforehand in registered designated centres. Some people are being accommodated in centres that require significant levels of restrictive practices and controls. These measures are deemed necessary in cases where people are assessed as being a danger to themselves or to others in the community. The Chief Inspector is concerned that these models of service may fall outside the definition of a designated centre, and that the regulatory framework to protect residents in such living environments may be inadequate." Health Information and Quality Authority 2017, *Overview of 2016 HIQA regulation of social care and healthcare services*. Ibid 79, page 25

<sup>81</sup> Senator Colette Kelleher, *Seanad Debates*, 5<sup>th</sup> April 2017, available <https://www.kildarestreet.com/sendebates/?id=2017-04-05a.224>

<sup>82</sup> Ibid

- <sup>83</sup> Health Service Executive, 2014. *Safeguarding Vulnerable Persons at Risk of Abuse National Policy and Procedures*. Ibid 21, page 6
- <sup>84</sup> Each service is required to appoint a Designated Officer (DO) with responsibility for receiving and reporting allegations of abuse, and preliminary assessments. The Community Health Organisation (CHO) area based SPT's role includes receiving reports of abuse, providing support and advice to service who report abuse on responding to abuse, and assess and manage complex cases.
- <sup>85</sup> Health Service Executive, 2014. *Safeguarding Vulnerable Persons at Risk of Abuse National Policy*, Ibid 21, page 6
- <sup>86</sup> Health Act (2007) Care and Support of Residents in Designated Centres for Persons (Children and Adults with Disabilities) Regulation 2013 and The Health Act, 2007 (Care and the Welfare of Residents in Designated Centres for Older People) Regulations 2013
- <sup>87</sup> Health Service Executive, 2005. *Trust in Care*. Available at [https://www.hse.ie/eng/staff/Resources/hrppg/Trust\\_in\\_Care.pdf](https://www.hse.ie/eng/staff/Resources/hrppg/Trust_in_Care.pdf) [accessed 18/06/2017]
- <sup>88</sup> Áras Attracta Swinford Review Group, 2016. *Time for Action – Priority actions arising from national consultation*. <http://www.hse.ie/eng/services/publications/Disability/AASRGtimeforaction.pdf> [accessed 20/06/2017], page 11
- <sup>89</sup> IHREC, 2017. Ibid 42
- <sup>90</sup> Siggins, L. (26<sup>th</sup> February 2015) "Hospitals breaching human rights of the elderly, GP says", *Irish Times* available at <http://www.irishtimes.com/news/ireland/irish-news/hospitals-breaching-human-rights-of-the-elderly-gp-says-1.2119264>
- <sup>91</sup> HSE, 2016, *National Consent Policy*, available at [http://www.hse.ie/eng/services/list/3/nas/news/National\\_Consent\\_Policy.pdf](http://www.hse.ie/eng/services/list/3/nas/news/National_Consent_Policy.pdf) [accessed 23/06/2017] and Medical Council, 2016. *Guide to Professional Conduct and Ethics for Registered Medical Practitioners 8<sup>th</sup> Edition 2016*, available at <https://www.medicalcouncil.ie/News-and-Publications/Reports/Guide-to-Professional-Conduct-and-Ethics-8th-Edition-2016-.pdf> [accessed 23/06/2017]
- <sup>92</sup> *Sage Annual Report*, Ibid 38
- <sup>93</sup> The NTPF, an independent statutory body, has been designated by the Minister for Health pursuant to Section 40 of the Nursing Homes Support Scheme Act 2009 as a body authorised to negotiate with proprietors of designated centres for older people to reach agreement on the maximum price(s) that will be charged for to Nursing Homes Support Scheme residents.
- <sup>94</sup> Sage Support & Advocacy Service for Older People (2016), *Responding to the Support & Care Needs of our Older Population*, Ibid 10.
- <sup>95</sup> HIQA, 2016. *National Standards for Residential Care Settings for Older People 2016* <https://www.hiqa.ie/sites/default/files/2017-01/National-Standards-for-Older-People.pdf> [accessed 22/06/2017]
- <sup>96</sup> See Appendix 7C, HIQA recently sought an order to cease admissions to a HSE run facility due to lack of compliance with regulations impacting on the quality of life of people in receipt of care.
- <sup>97</sup> Charges can range from €100 per month to €100 per week as in Sage Support & Advocacy Service for Older People, 2016. *Responding to the Support & Care Needs of our Older Population*. Ibid 10, page 30
- <sup>98</sup> Sage Support and Advocacy Service (2016) *The Nursing Home Support Scheme – Charges and Related Issues* Discussion Paper, Ibid 12.
- <sup>99</sup> Sage Support & Advocacy Service for Older People, 2016. *Responding to the Support & Care Needs of our Older Population*. Ibid 10
- <sup>100</sup> "Illustrative example: A 61-year old man placed in a nursing home following a period in hospital. Prior to coming to the nursing home, he used to walk to the village each day to buy the newspaper and cigarettes. His contribution to the nursing home charge is €143.30/week and he is also asked to pay a €30 weekly charge for 'social services charge' He has no money left for cigarettes or newspapers. Medication fees and transport charges are not included in his weekly contribution. There is no place near the nursing home where he could walk to buy anything and the Nursing Home will not allow him to leave the nursing home unaccompanied – this means that every time he wants to go out socially, he has to pay for a taxi and companion which he clearly cannot afford. He gets extremely frustrated that he has to live so far away from his familiar place, and has difficulty (understandable) in accepting that almost his entire income is taken for fees and charges." Sage Support and Advocacy Service (2016) *The Nursing Home Support Scheme – Charges and Related Issues* Discussion Paper, Ibid 12, page 12
- <sup>101</sup> Sage Support and Advocacy Service (2016) *The Nursing Home Support Scheme – Charges and Related Issues* Discussion Paper, Ibid 12, page 3

<sup>102</sup> “The cost of providing care in a public long-stay residential centre at present ranges from €884 to €2,089 per week. The approved rate for private nursing homes operating under the Government’s Fair Deal scheme runs from €685 to €1,325 per week. Public nursing home bed costs €700 more than private sector” Wall, M. (5<sup>th</sup> October 2016). “Public nursing home bed costs €700 more than private sector”, *Irish Times* available at <https://www.irishtimes.com/news/ireland/irish-news/public-nursing-home-bed-costs-700-more-than-private-sector-1.2816765> [accessed 23/06/2017]

<sup>103</sup> Sage Support & Advocacy Service for Older People, 2016. *Responding to the Support & Care Needs of our Older Population*. Ibid 10

<sup>104</sup> Cahill, S. et al. 2013. *An Irish National Survey of Dementia in Long-Term Residential Care* Ibid 20, page 2

<sup>105</sup> Sage Support & Advocacy Service for Older People, 2016. *Responding to the Support & Care Needs of our Older Population*. Ibid 10; Sage Support and Advocacy Service, 2016. *The Nursing Home Support Scheme – Charges and Related Issues* Discussion Paper, Ibid 12.

<sup>106</sup> The State is required under Section 42(1) of the *Irish Human Rights and Equality Commission Act (2014)* to ensure that all public bodies, in the performance of their functions, eliminate discrimination, promote equality of opportunity and treatment, and protect human rights.

<http://www.irishstatutebook.ie/eli/2014/act/25/enacted/en/pdf> [accessed 23/06/2017]

<sup>107</sup> IHREC has stated that public bodies must fulfil their Public Sector Duty obligations whether services are provided directly by the State or through a non-state actor. See IHREC, 2017. Ibid 42

<sup>108</sup> Áras Attracta Swinford Review Group, 2016. *Time for Action – Priority actions arising from national consultation*. <http://www.hse.ie/eng/services/publications/Disability/AASRGtimeforaction.pdf> [accessed 20/06/2017]

<sup>109</sup> Adult Safeguarding Bill 2017, Section 9(1)(d)

<http://www.oireachtas.ie/documents/bills28/bills/2017/4417/b4417s.pdf>

<sup>110</sup> “The HSE’s safeguarding procedures are now being put in place and activated throughout Ireland. In order for these procedures to have ‘teeth’, however, they require to be placed on a statutory basis. This would ensure that they are fully implemented and supported by a comprehensive national training programme that is designed and delivered with the involvement of people with an intellectual disability.” Swinford Review Group, 2016. *Time for Action*, Ibid 108, page 4

<sup>111</sup> National Vetting Bureau (Children and Vulnerable Persons) Act 2012,

<http://www.irishstatutebook.ie/eli/2012/act/47/enacted/en/pdf>

<sup>112</sup> OHCHR, *Normative standards in international human rights law in relation to older persons: Analytical Outcome Paper*, August 2012, 31 as in Maeve O’Rourke, ‘Poor Continence Care: A Question of Dignity’. Working Paper, 2017.

<sup>113</sup> Office of the Ombudsman, 2015. *Learning to Get Better Executive Summary and Recommendations*. Dublin: Office of the Ombudsman <https://www.ombudsman.ie/en/Publications/Investigation-Reports/Health-Service-Executive/Learning-to-Get-Better/Learning-to-Get-Better-Summary.pdf> [accessed 20/06/2017]

<sup>114</sup> HSE Consumer Affairs, 2009. ‘Your Service, Your Say’ available at <http://www.cuh.hse.ie/Contact-Us/Compliments-Complaints/Your-Service-Your-Say-Policy.pdf> [accessed 23/06/2017]

<sup>115</sup> Office of Ombudsman 2016, *Annual Report 2016* [https://www.ombudsman.ie/en/Publications/Annual-Reports/2016-Annual-Report/media/ombudsman\\_annual\\_report\\_2016.pdf](https://www.ombudsman.ie/en/Publications/Annual-Reports/2016-Annual-Report/media/ombudsman_annual_report_2016.pdf) [accessed 14/06/2017], page 41

<sup>116</sup> Ibid

<sup>117</sup> Swinford Review Group, 2016. *Time for Action*, Ibid 108, page 104; Office of the Ombudsman, 2015. *Learning to Get Better*. Ibid 113, page 109; HIQA, 2015. *Report of the investigation into the safety, quality and standards of services provided by the Health Service Executive to patients in the Midland Regional Hospital, Portlaoise* available at <https://www.hiqa.ie/sites/default/files/2017-01/Portlaoise-Investigation-Report.pdf> [accessed 23/06/2017]

<sup>118</sup> As noted by the Irish Human Rights Commission in the submission to the UNCAT in 2011, HIQA is not empowered to submit proposals on existing or draft legislation. Irish Human Rights Commission, 2011. *National Human Rights Submission to the UN Committee Against Torture on the Examination of Ireland’s First National Report*, page 14. Available at [https://www.ihrec.ie/download/pdf/ihrc\\_report\\_to\\_un\\_committee\\_against\\_torture\\_april\\_2011.pdf](https://www.ihrec.ie/download/pdf/ihrc_report_to_un_committee_against_torture_april_2011.pdf) [accessed 20/06/2017]

<sup>119</sup> Accessible at <https://www.rte.ie/news/player/2014/1209/20694826-inside-bungalow-3/>

<sup>120</sup> HIQA May 2014 *Compliance Monitoring Inspection report Designated Centres under Health Act 2007, as amended for Centre ID ORG-0011215*, page 3, available at <http://www.inclusionireland.ie/sites/default/files/attach/article/1209/hiqa-26-may-2014.pdf>

- <sup>121</sup> HIQA January 2015 *Compliance Monitoring Inspection report Designated Centres under Health Act 2007, as amended for Centre ID OSV-0004910*, available at <https://static.rasset.ie/documents/news/4910-14-january-2015.pdf>
- <sup>122</sup> Áras Attracta Swinford Review Group was appointed by the HSE, and a *Trust in Care* investigation in the allegations of abuse was initiated following the broadcast of the *Inside Bungalow 3* programme
- <sup>123</sup> Áras Attracta Swinford Review Group, 2016. *What matters most*, page 165  
<http://www.hse.ie/eng/services/publications/Disability/AASRGwhatmattersmost.pdf> [accessed 20/06/2017]
- <sup>124</sup> Ibid, page 46
- <sup>125</sup> Ibid, page 46
- <sup>126</sup> Ibid, page 167
- <sup>127</sup> Áras Attracta Swinford Review Group, 2016. *Key Messages*, available at <http://www.hse.ie/eng/services/publications/Disability/AASRGkeymessages.pdf> [accessed 20/06/2017]
- <sup>128</sup> *Sage Annual Report*, Ibid 38
- <sup>129</sup> HIQA, 2016, *Compliance Monitoring Inspection report Designated Centres under Health Act 2007, as amended for Conna Nursing Home*, available at <https://www.hiqa.ie/system/files?file=inspectionreports/4447-Conna-Nursing-Home-23.04.2015.pdf>
- <sup>130</sup> HIQA, 2016, *Compliance Monitoring Inspection report Designated Centres under Health Act 2007, as amended for Sacred Heart Hospital*, available at <https://www.hiqa.ie/system/files?file=inspectionreports/0654-Sacred-Heart-Hospital-23.03.2016.pdf>
- <sup>131</sup> “Overall respondents were complimentary of staff but three consistent areas of concern/dissatisfaction were identified; the physical environment, meaningful engagement and staffing levels. Respondents articulated a clear desire for more privacy, more space, more sanitary facilities and somewhere to meet up and chat. Residents wanted more meaningful engagement and reported that they “had nothing to do”; this was also reflected in some of the relatives’ questionnaires.  
Concerns were raised as to the impact of staffing on residents’ choices and routines such as their personal hygiene, access to snacks and fluids, and having to wait for “long periods” for staff assistance. The findings of this inspection would support and reflect the majority of these experiences.” HIQA, 2015, *Compliance Monitoring Inspection report Designated Centres under Health Act 2007 as amended for St. Joseph’s Hospital* <https://www.hiqa.ie/system/files?file=inspectionreports/613-St-Joseph%27s-Hospital-18.06.2015.pdf> page 3
- <sup>132</sup> Ibid
- <sup>133</sup> Deegan, G. (12<sup>th</sup> June 2017) “Elderly residents at Clare hospital stay in bed all day as ‘they’ve nowhere else to go’, court hears.” *The Journal.ie* available at <http://www.thejournal.ie/st-josephs-ennis-courts-3440549-Jun2017/>
- <sup>134</sup> Dunnion, M. (2<sup>nd</sup> June 2017), “Improvement of Lives through the Regulation of the Disability Sector”, *Irish Examiner*, available at <http://www.irishexaminer.com/viewpoints/analysis/improvement-of-lives-through-regulation-of-the-disability-sector-451496.html>
- <sup>135</sup> HIQA, 11<sup>th</sup> July 2016. *Disability publication statement 11 July 2016* available at <https://www.hiqa.ie/hiqa-news-updates/disability-publication-statement-11-july-2016>; O’Regan, E. (11<sup>th</sup> July 2016). “HSE takes over the running of three residential centres for people with autism after HIQA finds serious failings”, *Irish Independent*, available at <http://www.independent.ie/irish-news/hse-takes-over-the-running-of-three-residential-centres-for-people-with-autism-after-hiqa-finds-serious-failings-34873555.html>
- <sup>136</sup> HIQA, 29<sup>th</sup> August 2016. *Disability publication statement 29 August 2016*, available at <https://www.hiqa.ie/hiqa-news-updates/disability-publication-statement-29-august-2016>
- <sup>137</sup> HIQA, 9<sup>th</sup> June 2017, *HIQA publishes inspection reports for Camphill Communities of Ireland, Ballytobin 9 June 2017* available at <https://www.hiqa.ie/hiqa-news-updates/hiqa-publishes-three-inspection-reports-camphill-communities-ireland-ballytobin-9>