Submission to the Department of Health on Deprivation of Liberty Safeguards

Family Carers Ireland (FCI) welcomes the opportunity to submit our views to the Department of Health on the development of Deprivation of Liberty Safeguards (DoLS). FCI acknowledges the significant challenges involved in developing legislative provisions for DoLS and the commensurate need to align these with the UN Convention on the Rights of People with a Disability and the European Convention on Human Rights. We recognise the many people affected by these proposals – those lacking capacity, or whose capacity is in question, their families and carers, healthcare professionals, staff of residential centres and legislators – however in this submission FCI focuses specifically on the needs of family members and carers, who in many cases will act as power of attorney, or an assistant decision-maker, a co-decision maker or a decision-making representative when the provisions of the Assisted Decision-making (Capacity) Act 2015 (hereafter Capacity Act) are commenced, and are likely to be the primary caregivers of people whose expressed wish is to be cared for at home[1]. FCI understands that the DoLS will give legal effect to the procedures which must be followed in order to lawfully deprive a person who lacks capacity of their liberty where it is in their best interest to do so. In this regard we make the following comments and recommendations.

- FCI fully supports the introduction of DoLS providing a legal framework for the protection of people who are lacking capacity, or whose capacity is being questioned, from their unlawful detention in a residential care centre. We agree that not only the absence of safeguards but heretofore the legal vacuum regarding consent and decision-making, where consent is given by a third party with no legal authority, is placing people at greater risk of being inappropriately deprived of their liberty. We stress, however, that in the vast majority of cases families act in the best interest of their loved one, and up to now have had to cope with legal deficits which have forced them, through no fault of their own, to make decisions on behalf of their loved one without legal protection, support or guidance. While FCI wholeheartedly respects the guiding principles of the Capacity Act, including ensuring that the *'will and preferences, beliefs and values of the person is central to all decision making'*, we expect that the same consideration will be extended to ***families who must be free to decide if, and to what extent, they agree to provide care*** in respect of a loved one whose preference is to be cared for at home. To this end, we recommend that the legislation on the Capacity Act and the forthcoming Homecare Scheme include a statutory definition of where the ultimate responsibility for care should be located. We believe that there would be support for a system which located primary responsibility with the family with a secondary duty on the state to support this endeavour in specific ways (as well as acting as a provider of last resort where the family is unwilling or unable to meet the need).

- The anomaly and systemic bias towards long-term residential care for older people through the provision of Fair Deal with no equal right to meet the care preferences of people wishing to remain at home 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. It is ***critical that Government enact legislation that will give a statutory, demand-led entitlement to home care and place care in the home on an equal footing with nursing home care***, enabling people whose express preference is to remain at home to do so.

- While the DoLS will rightly focus on preventing the inappropriate admission to residential care, it must also address a significant ***discrepancy in Fair Deal legislation, where no provision is made to allow a person to leave a nursing home if they change their mind or express a wish to return home.*** The complications arising from this are compounded where a person's financial contribution

---

[1] Research consistently shows the preference of older people to remain living at home (Donnelly et al, 2016) with commensurate implications for the need for informal care – 80 percent of care in Europe is provided by informal carers (Hoffman and Rodrigues, 2010; Cardi, 2018, p.3).

through Fair Deal was based on a deferred loan in respect of the value of their home or where the home has been sold. Difficulties will also arise where a person entered a nursing home due to the unsuitable living conditions of their own home, but now wish to return home. In these cases people could find themselves without any support, as home care providers will be prevented from entering the home under HSE health and safety policies. These practical issues illustrate the potential and far-reaching implications of DoL legislation, and point to the role that other departments not traditionally associated with care must play, for example, housing adaptation grants administered through the Department of Housing, Planning and Local Government; transport provided by the Department of Transport and tax reliefs offered through Revenue.

- By not including acute hospitals within the provisions of the DoLS the department is failing to recognise a ***significant and increasing cohort of vulnerable adults whose discharge from hospital is delayed because there is no alternative care arrangement in place for them***. In fact, it is now standard practice to discharge patients waiting for home care packages to step-down, transitional care beds, from where they are eventually transferred to a nursing home as their dependency increases. In these cases the system fails to respect, protect and/or uphold the patient's preference for care.

- The DoLS are dependent on the use of the decision support mechanisms of the Capacity Act and enduring powers of attorney to avoid overburdening the courts system. The Capacity Act requires court-appointed decision-makers (co-decision-makers and decision-making representatives) to submit an annual report to the Office of Decision Support on the performance of his or her functions and stipulates that the court, on appointing a decision-maker, may require them to give such security as it considers appropriate in relation to the proper performance of their functions. FCI is concerned with the lack of detail provided with regard to such annual reports, the level and type of information required and the additional burden this places on decision-makers who will already be fulfilling the incredibly arduous task of acting on behalf of the individual concerned, without support or recognition. The awareness campaign referred to in the draft Heads of Bill (point 2, p.10) will be of little value if the basic ***supports required to enable decision-makers to carry out their role*** is lacking and people are therefore simply unwilling to enter into such arrangements.

- The Capacity Act provides for multiple decision-makers to be assigned with responsibility for different levels of decision making (i.e. co-decision maker, decision-making representative etc.) and for different types of decision (i.e. financial, health, housing). It is inevitable that such layers of decision making will lead to conflict and ***disagreement among decision-makers as well as the potential for overlap across decision-making categories***. For example, decisions relating to Fair Deal will overlap with financial and health related decision-making powers. This complexity is further complicated when a power of attorney is also present.

- Persons who are involuntarily admitted for mental health treatment under the Mental Health Act 2001 (circa 10%) are by definition deprived of their liberty. Consequently, to protect the rights of patients and to comply with our constitutional and international legal obligations, all involuntary admissions are periodically reviewed by an independent Mental Health Tribunal. Under the 2001 Act, 'voluntary patients' do not have their admission to an approved centre independently reviewed because it is commonly understood that a voluntary patient is not being detained against their will, and have given consent to their treatment. The difficulty is that the ***definition of 'voluntary patient' includes persons who are 'incapacitated but compliant' and by consequence are in fact detained and therefore deprived of their liberty.*** The Supreme Court considered the definition in the case of EH v St Vincent's Hospital and Ors[2009] and held that *'the particular meaning of "voluntary patient" does not describe a person as one who freely and voluntarily gives* *consent to an admission order. Instead the express statutory language defines a "voluntary patient" as a person receiving care and treatment in an approved centre who is not the subject of an admission order or a renewal order*.' Such a position leaves Ireland open to a claim of breach of the European Convention on Human Rights and therefore represents a challenge to DoLS. A decision by the Court of Appeal in recent weeks (28 Feb 2018) PL -v- Clinical Director of St. Patrick's University Hospital & Anor offers further clarification on the deprivation of liberty of voluntary patients. The man at the centre of the case, "PL", had been refused permission to leave St Patrick's University Hospital, while a voluntary patient. The Court found that "PL" had been prevented from leaving the hospital, in a way which interfered with his personal liberty without a legal basis, and noted that "*voluntarism remains a cornerstone of our system of medical treatment."* It is therefore important that special provision be made within the DoLS to protect the rights of voluntary patients receiving mental health treatment.

- Consideration must be given to the ***financial and caseload pressures that the DoLS will place on an already overburdened and under-funded sector.*** For example, in the UK a Supreme Court judgement in March 2014 lowered the interpretation of 'deprivation of liberty', resulting in more people being identified as having been deprived of their liberty. While the UK's Department of Health gave councils £25 million in 2015-16 to meet the associated costs, the Local Government Association has estimated that DoLS are costing councils £127 million a year. There were eight times as many DoLS applications in care homes or hospitals from April to December 2014 than in the whole of the 2013-14 financial year, according to official figures. This means average monthly referrals were ten times higher in 2014-15 than 2013-14. In Kent County Council alone, the number of applications for DoLS assessments increased from 286 in 2013-14 to 4,870 in 2015-16, with the average cost of an individual DoLS assessment estimated to be £460. Other indirect costs will arise from pressures on the court system, the cost of undertaking capacity assessments and the natural increase in informal care that will be required as a result.

- The draft Heads of Bill is 47 pages long and contains 13 heads. In addition to its length, its ***wording is overly complicated and not user-friendly for those who are covered by its provisions*** and those conferred with particular roles under it. The accessibility of the Bill should be considered, and practical advocacy supports and easy-to-read guides put in place, to ensure that the persons whom the Bill is designed to protect are supported to understand it, as well as the implications of decision-making arrangements. Equally, the family members, carers and those who are likely to be assigned as decision-makers should also be supported to fully understand their role and responsibilities and to address any practical difficulties they may encounter.

About FCI
FCI is a national membership charity for carers. For 26 years we have worked to improve supports, services and recognition for the 355,000 family carers[2] providing support to a family member or friend who is ill, frail, disabled or has mental health difficulties. Through our network of 22 resource centres and 66 support groups we engage with approximately 20,000 family carers throughout Ireland every year. FCI also provides in-home respite and homecare in each of the 9 CHO regions as an approved HSE provider.

Contact:
Clare Duffy – Policy and Public Affairs Manager
Email: cduffy@familycarers.ie
Tel: 086 7707231

---

[2] National Carers Strategy (2012) defines a Family Carer as '*someone providing an ongoing significant level of care to a person in need of that care in the home due to illness or disability or frailty'.*