

## **A Regulatory Framework for Adult Safeguarding**

### **Care Alliance Ireland Submission**

#### **Focus on the points pertaining to family carers**

#### **July 2020**

Care Alliance Ireland are pleased to make this short submission to the Law Reform Commission regarding the Issues paper "A Regulatory Framework for Adult Safeguarding".

A family carer is a person who provides care and support to a person with a disability, mental health difficulty, long-term/ chronic illness or requires care due to concerns due to ageing<sup>1</sup>. As such, many of the care recipients of family carers could be understood to come under the umbrella of ‘vulnerable’ in some way. In general we do use the label ‘family carer’, even though the usage of the term can be challenging, in particular with regard to the disabled and mental health communities<sup>2</sup>. We understand and support the progression of policies which aim to enable people with disabilities to be seen as people first, and who have primary agency in their own lives.

However, many family carers, and the organisations which support them (many of whom are members of our alliance), have some concerns when it comes to the subject of consent, decision-making and safeguarding. It is these, in relation to this most recent Issues Paper, that this short submission will focus on. Balancing the needs of people who require some level of safeguarding along with the needs of their families and caregivers is not easy, and discussions on the subject often yield more questions than answers. This submission will reference the particular proposed questions for respondents from the Issues Paper where relevant, along with some other concerns which the Commission should take into consideration.

#### **General Points**

- 1) Many family members have been assisting their loved ones (including parents, children, siblings and spouses) with decision making for most, if not all, their lives. Some will have come to this role in recent times, and will have the benefit of having many years of knowing their loved one where they had no reason to make decision on their behalf, but have a strong understanding of their needs, wishes and preferences. This knowledge, drawn from many years of caring for and about their family member, must be respected as genuine. We have heard from family carers that this is sometimes not

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<sup>1</sup> Central Statistics Office, ‘Census 2016’ (Ireland: Central Statistics Office, 2017).

<sup>2</sup> Zoe Hughes and Liam O’Sullivan, ‘Defining and Profiling Family Carers: Reflections from Ireland’, *International Journal of Care and Caring* 1, no. 3 (2017): 421–27; J Henderson, “‘He’s Not My Carer- He’s My Husband’”: Personal and Policy Constructions of Care in Mental Health’, *Journal of Social Work Practice* 15, no. 2 (2001): 149–59.

the case, with health and social care professionals in particular choosing to ignore their inputs, and causing more harm than good. An example of this is a situation whereby a person with a lifelong intellectual disability was an in-patient in a hospital for a specific medical reason, and their family member was not included in any discussions with their medical team, despite repeatedly informing the nursing staff of the communication and comprehension difficulties the patient had. In some cases family carers have been labelling as ‘difficult’ and ‘controlling’, undermining the overarching sentiment within the National Carers Strategy whereby family carers should be ‘recognised and respected as key care partners’<sup>3</sup>.

- 2) The vast majority of family carers act solely in the best interests of the person they care for. We appreciate that abuse happens within caring contexts, however we dispute the idea that it is a regular occurrence. Some family carers have reported feeling like health and social care professionals, along with policy makers in these contexts, can suggest that by taking responsibility for certain facets of life for their loved one (such as financial, medical or educational) they are attempting to control or abuse them.
- 3) There is a piece of work that must be undertaken to bring family carers along- in particular older family carers who were told in the past that their loved one ‘would never’ be able to make their own decisions or live independently – with regards to decision making, capacity, and adult safeguarding.

## **Questions posed by the Issues paper**

### **Issue 1:**

Q. 1.1 Do you consider that the proposed guiding principles, as set out above in paragraph 1.14 of the Issues Paper, would be a suitable basis to underpin adult safeguarding legislation in Ireland?

Broadly, yes. However, we also note that specific mention is given in the example of the Adult Support and Protection (Scotland) Act 2007 (paragraph 1.12) that regard must be given to the ‘*views and feelings of the adult’s nearest relative, primary carer, a guardian or attorney, and any other person who has an interest in the adult’s well-being or property*’. We would support the inclusion of a similar guiding principle here.

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<sup>3</sup> Department of Health, ‘The National Carers’ Strategy’ (Department of Health, 2012).

Q. 1.2 Do you consider that additional guiding principles should underpin the legislation? If yes, please outline the relevant additional guiding principles.

As above.

**Issue 2:**

Q. 2.3 Do you consider that the Commission has, in Issue 2 of the Issues Paper, defined the following terms with sufficient clarity:

(a) “safeguarding”;

(b) “abuse” and “harm” (including whether you consider that the definition of “abuse” should include “harm” or whether “abuse” and “harm” should be separately defined);

(c) “neglect”;

(d) “capacity”.

With regards to the legality of definitions, we do not have sufficient expertise in this area to offer guidance. However, with regards to the issue of capacity, family carers have reported feeling that their longstanding understanding of the capacity of their family member to make certain decisions is often ignored, or dismissed. This does not mean that family carers understanding of the capacity of the person they care for should be the only perspective considered, but that their understanding built up through many years of care and communication should be included as a key aspect in any robust evaluation of capacity.

**Issue 5:**

Q. 5.1 The Commission has discussed the following 5 possible institutional or organisational models for the regulation of adult safeguarding:

- Establishing a regulatory body within the Health Service Executive
- Establishing a regulatory body as an executive office of the Department of Health
- Establishing a regulatory body as an independent agency
- Amalgamating a regulatory body with an existing agency
- Conferring additional regulatory powers on an existing body or bodies.

In your view:

(a) which of the above is the most appropriate institutional or organisational model for the regulation of adult safeguarding?

Given the broad remit of adult safeguarding, we would be of the opinion that establishing a regulatory body as an independent agency is the most appropriate model. The reason for this is that most services which are provided for those adults who would come under the auspices of adult safeguarding policy are either directly provided by, or funded by, either the Department of Health or the HSE. Many families who may wish to report issues of safeguarding are in receipt of supports or services from either of these

bodies and may feel that they risk losing these services if reporting concerns regarding family members. Independence is critical for such a body to operate well.

(b) do you consider that any of the models discussed would be completely inappropriate?

As above, we feel the establishment of models involving the creation of a body within existing HSE or DoH structures is inappropriate.

## Background Information on Care Alliance Ireland

There are approximately 391,000 family carers in the Republic of Ireland. Family carer support is provided by a number of organisations, including those dedicated solely to carer support and others who support carers as part of their response to individuals with specific conditions.

Care Alliance Ireland is the National Network of Voluntary Organisations supporting family carers. Our vision is that the role of family carers is fully recognised and valued by society in Ireland. We exist to enhance the quality of life of family carers. We achieve this by supporting our 95+ member organisations in their direct work with family carers through the provision of information, developing research and policy, sharing resources, and instigating opportunities for collaboration.

Our legitimacy derives in part from our membership base which includes a wide range of organisations currently providing services to Ireland’s family carers. Our membership is comprised of both large and small, regional and national organisations. We work with organisations in order that they can enhance the information and supports they provide to family carers. We provide them with opportunities to collaborate on initiatives including National Carers Week, a multi-agency and multi-disciplinary Family Carer Research Group, and joint policy submissions. We actively encourage collaboration in all our projects. We provide cohesion to those organisations working to support family carers. We commission relevant research that supports quality interventions in the lives of family carers.

By focusing on these functions we enable more of our member’s resources to go directly to coal face services.

### Contact

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