Opening statement by John Dunne, Chief Executive, Family Carers Ireland to the Oireachtas Committee Children, Disability, Equality, Integration and Youth hearing on Pre-legislative scrutiny of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021 on 15th February, 2022.

Thank you for the opportunity to contribute to the Committee's pre-legislative scrutiny of the Assisted Decision-making (Capacity) (Amendment) Bill 2021.

Family Carers Ireland is the national charity supporting the 500,000 family carers across the country who care for loved ones such as children or adults with physical or intellectual disabilities, frail older people, those with palliative care needs or those living with chronic illnesses, mental ill-health or addiction. Every family carer wishes the best outcome for their 'relevant persons' as defined in the Act and so they want this legislation to be a success. But the focus of our discussion today is on the actual legislation not the aspiration underpinning it. We have significant concerns in this regard and I would like to highlight three of these to you today.

'Imminent risk of serious harm'

Head 27 of the Assisted Decision-making (Capacity)(Amendment) Bill 2021 proposes to delete a provision of the 2015 Act relating to the use of restraint in private settings by decision supporters. This is a sensitive topic perhaps conjuring up images of people locked in rooms or tied to radiators. The reality can be a good deal more mundane – a locked front door at night, a stair guard or a side rail on a bed. The original Act is quite explicit that restraint should only be used where "the decision-making representative reasonably believes that it is necessary to do the act in order to prevent an imminent risk of serious harm to the relevant person or to another person" (section 44.5(b)). Deleting this provision implies that anyone who needs <u>any</u> restraint for their own safety or the safety of others will have to be placed in an institutional setting. This surely cannot be the intention.

The Heads of Bill notes that "the use of restraint in institutional settings .. will continue to be governed by relevant legislation and guidelines". Our understanding is that current guidelines on 'Deprivation of Liberty' in institutional settings have not been amended to reflect the provisions of the 2015 Act and that this will not have happened before the proposed commencement date of the legislation. Thus the proposal appears to be that some relevant persons will have to be moved to institutional care because of legal 'safeguards' which will not apply in that institutional setting - indeed the Heads of Bill wording clearly distinguishes between legislation and guidelines. If this amendment goes ahead we anticipate that it will to several different types of legal challenge.

Payment of DMR Expenses

Head 25 of the Amendment Bill 2021 makes provision for the Decision Support Service (DSS) to pay the expenses and remuneration of decision-making representatives appointed by the court from the panel established by the DSS in cases where the court finds that such expenses and remuneration cannot be met from the assets of the relevant person due to an insubstantial estate. We note that

there is no provision for payment of the expenses and remuneration of family carers acting as decision-making representatives (estimated at 67% of total number by DSS) even though they will be expected to perform the same duties and submit to the same accountability arrangements as 'strangers' appointed by the DSS. This seems to us to be a case of clear discrimination on the basis of family status.

Inadequate transition provision

Our third major concern with the Bill relates to something it omits rather than something it contains. We have been asking since 2014 for a transition arrangement for life-time caring families equivalent to the one provided for Wards of Court under the original Act. The DSS' estimate of need for Decision-making Representatives (DMRs) in 2022 is in excess of 18,000 (9% of the baseline population of 204,171). It expects to appoint 1,605 DMRs (approximately 9% of estimated need) in its first year of service (i.e. to mid-2023). This suggests that it will take 10 years to meet the 2022 level of need (ignoring projected demographic increases over that decade). Given that the spirit and intent of the legislation is to only make DMR arrangements where absolutely necessary what is going to happen to families who need a DMR but find themselves at the back of a 10 year queue? In the absence of a clear answer to this question we continue to call for an amendment to the 2015 Act to provide for a transition arrangement for caring families.

Thank you once again for this opportunity to contribute to your deliberations. I will be very happy to elaborate on any or all of these issues later in the proceedings.