

Submission to the Joint Committee on Disability Matters on the lived experience of people with a disability and their family carers

Family Carers Ireland is a national charity that works to improve supports and recognition for families and friends caring for someone who is ill, frail, disabled or has a mental health difficulty. We welcome the opportunity to set out a number of areas we believe should be considered in the work programme of the Joint Oireachtas Committee on Disability Matters (hereafter, the Committee) and be reflected in its Terms of Reference. The submission is based on our experience of supporting and advocating for Ireland's 355,000¹ family carers² who provide some 16 million hours of unpaid care each week while saving the State over €10 billion each year in avoided health and social care costs³.

While the UNCRPD is underpinned by the principles of individual autonomy, independence, freedom to make one's own choices, accessibility and full inclusion in society, the Committee must recognise that where a person with a disability needs fulltime care, then the realisation of these principles is intrinsically linked to an assurance that the same principles apply to their family carer(s). While *Family Carers Ireland* acknowledge that the fundamental remit of the Committee is to consider matters relating to people with a disability, it must also recognise that where a family carer is present, then their needs must be equally considered. Importantly however, while some aspects of disability and carer policy are often considered as two sides of the same coin, the respective perspective of the carer and that of the person with a disability can vary greatly – a point the Committee will need to be cognisant of in carrying out its work.

This submission begins by providing an overview of the state of caring in Ireland in 2020 and goes onto highlight six areas *Family Carers Ireland* would like to see included in the Committee's Terms of Reference. Two of these areas (iv and vi) illustrate where divergent perspectives between disability and carer policy may exist. Given the importance of the Assisted Decision-making (Capacity) Act 2015 much focus is given to the practical considerations of the Act for family carers.

Context: State of Caring 2020⁴

In early 2020, before the outbreak of COVID-19, *Family Carers Ireland* undertook Ireland's first national State of Caring survey. Completed by some 1,250 family carers the survey's findings paint a stark picture of carers' lives pre-COVID, with many struggling financially, facing indebtedness and without access to essential supports. Before the findings of the State of Caring survey were published, the COVID pandemic reached Ireland and the situation that carers were in when they completed the survey suddenly became very different. The blanket withdrawal of supports such as homecare, respite, personal assistance hours and residential care during lockdown forced many carers to care alone, around the clock and without the support of extended family or friends. Parents of children with a disability lost the routine and relief of school, day services and essential therapies, placing the child at serious risk of regression. Older carers and those with underlying health conditions were expected to cocoon, isolated and became reliant on others. Even carers who were coping relatively well prior to the pandemic became mentally and physically drained, with many struggling to maintain their caring role. In response, *Family Carers Ireland* extended the State of Caring research to include a special module on carers' experience of 'Caring Through COVID'. Some 1,307 carers responded to this additional survey during April and May. The table below summarises some of the key findings.

¹ CSO Irish Health Survey (2015) shows 10 percent of the population aged over 16 are carers. If extrapolated to the national population, this means Ireland has close to 355,000 carers.

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'.

³ Based on Census 2011 and €12 per hour replacement care cost rate.

⁴ Family Carers Ireland (2020) State of Caring 2020. Dublin: Family Carers Ireland.

State of Caring before COVID	Caring Through COVID
<ul style="list-style-type: none"> - 70% carers find it hard to make ends meet; - 21% carers who struggle financially cut back on essentials such as groceries and heating; - 55% carers have given up paid employment to care for a loved one; - 29% carers live in households with a total income of less than €20,000 per year; - 56% carers feel their financial situation is affecting their health; - 75% carers experience difficulties accessing services; - 75% carers who juggle caring with full-time employment provide 50+hrs care each week; - 70% carers have missed out on support as a result of not getting the right information; - 57% carers have experienced or are likely to experience debt as a result of caring. 	<ul style="list-style-type: none"> - 84% carers worry about getting the virus and not being able to look after their loved one; - 63% are concerned about a decline in the health of their loved one; - 63% experienced delays or cancellations of medical appointments, treatments or surgery; - 61% believe there isn't enough information and advice for family carers about COVID-19; - 60% worry about a decline in their own mental health and wellbeing; - 56% are concerned about their loved one displaying increased challenging behaviours; - 47% are unable to access appropriate PPE; - 43% fear that normal services will not be restored after the crisis; - 39% worry about the financial costs of COVID; - 26% worry about access to essential supplies such as groceries.

Issues for consideration by the Committee

(i). Decimation of transport schemes for people with a disability and their carers

Prior to 2013 three separate transport schemes existed to support people with a disability and their carers (i) the Mobility Allowance, (ii) Motorised Transport Grant and the (iii) Disabled Drivers and Disabled Passengers scheme. In 2013 following a finding from the Equality Tribunal the Mobility Allowance and Motorised Transport Grant, both administered by the HSE, were immediately withdrawn on the grounds of age discrimination. Despite a commitment from Government that both schemes would be replaced by a single 'Transport Support Scheme' this has failed to materialise and has led to the illogical situation whereby those who received a Mobility Allowance prior to 2013 have been allowed to keep it while others now equally in need are locked out. It also means that the only transport support available to families since 2013 has been the Disabled Drivers and Passengers Scheme operated by Revenue which is available only to those with severe physical disabilities, with no support available to those with an intellectual disability or cognitive impairment. In July 2020 following a Supreme Court ruling, the issuing of Primary Medical Certificates – a prerequisite of the Disabled Drivers and Disabled Passengers scheme – was suspended with immediate effect, in effect rendering the only remaining transport scheme available to people with a disability void. This comes at a time when the service-based transport relied on by some 8,000 people with a disability is being withdrawn or reduced due to COVID, with the HSE's Framework for the Resumption of Adult Disability Day Services stating that '*families of services users should be asked to provide this transport*' (p.15). Given the withdrawal of transport to day services and public health advice to avoid public transport, it is now more imperative than ever that the Transport Support Scheme be introduced.

(ii). Resumption of disability services and respite following lockdown

Even before the COVID crisis, many carers already experienced difficulty accessing supports such as disability services, homecare or respite⁵. During lockdown, this became even worse as services were withdrawn and carers were without the support of extended family and friends. As we emerge from lockdown, many carers are feeling exhausted, burnt out, isolated and now gravely concerned that the

⁵ State of Caring (2020): Family Carers Ireland.

supports and services they relied on before the pandemic will not return. The publication of the HSEs 'Resumption of Adult Disability Day Services Framework' reinforces this fear by stating that 'service capacity will be reduced' (page 4) and 'service users will receive a reduced quantum of service supports' (page 5). We are also deeply concerned that respite care, which was already wholly inadequate prior to the pandemic, will be virtually non-existent, as social distancing means that the already inadequate respite provision will be even further curtailed. Notwithstanding the very real challenges that COVID and the subsequent public health guidance present to service providers, the COVID crisis should not be used as a reason to rationalise services, but rather as an opportunity to improve them. Where residential or centre-based services are no longer available, in-home alternatives should be considered but only where they meet the needs of the service user and their family. In a similar way to how creches and childminding facilities have reopened using play-pods, social pods could be considered for adults with a disability who enjoy peer and social support. Where residential respite is limited alternative models of respite should be considered including supported hotel stays, in-home respite, host family respite, day break services or summer/weekend camps. We cannot allow people with a disability and their families to suffer further as a result of COVID-19.

(iii). Waiting lists for essential health therapies for children with a disability (PFG)⁶

Before COVID, almost 215,000 children were on a waiting lists for essential health care services including hospital treatment, speech and language, occupational therapy, physiotherapy and psychology with significant variation in waiting times across the country⁷. This figure is likely to increase substantially following the lifting of COVID restrictions. The delay, which is measured in years rather than months, in accessing these essential supports mean that many of Ireland's most vulnerable children are being denied the early intervention support that is critical to their development and placing them at serious risk of regression. While we acknowledge the Programme for Government commitment to address waiting times for the Assessment of Need legislated for in the Disability Act 2005, we are sceptical that this can be achieved through the public system alone. Rather *Family Carers Ireland* is calling for additional funding for the National Treatment Purchase Fund to enable it to be extended to include clearing the waiting lists for paediatric interventions and essential therapies by treating these children through the private system. Children, particularly those with disabilities, have been most severely affected by the blanket withdrawal of services during the COVID crisis. Every effort must now be made to ensure the long-term impacts of the withdrawal of services are minimised.

(iv). Cost of Disability / Cost of Caring:

The Department of Employment Affairs and Social Protection's study to examine the 'Cost of Disability' commissioned in 2019 is now well underway. *Family Carers Ireland* are disappointed that the study will examine only the cost of disability, rather than the cost of disability and caring as was committed to by Minister Regina Doherty during her closing speech at the annual Prebudget Forum in Dublin Castle in 2018. While the economic implications of providing care are well recognised - higher household costs; being forced to pay-out-of-pocket for services that have been cut back or withdrawn; the opportunity cost of having to give up work, reduce hours of work or forego employment opportunities in order to provide care; and the long term financial implications that can result due an inability to save, make provision for the future and the loss of pension entitlement –there is little research on the direct costs incurred by family carers in contributing to the care of a loved one. While relatively hidden, the role of family in subsidising the living costs of a loved one with a disability is a significant feature of Irish society. For example, many adults reliant on a Disability Allowance of €203 per week can't afford to live independently and so remain living with parents or family. As well as providing for their housing needs, family often meet other costs such as homecare, food, transport, heating, medicines, laundry, waste collection and respite charges. *Family Carers Ireland* believes that

⁶ The Programme for Government commitment refers only to extending the NTPF to secure timely assessment for both child and adult psychological services.

⁷ Figures released through a series of Parliamentary Questions raised by Deputy Stephen Donnelly in December 2019.

as well as identifying the additional costs associating with living with a disability, the Cost of Disability study should also examine the absorption of these costs i.e. by whom are they paid.

(v). ‘Just transition’ provisions for family carers who are being penalised for unavoidable costs

Family Carers Ireland is fully supportive of efforts to reduce our carbon emissions and invest in sustainable and renewable energy generation. However, we believe that the cost of climate action must not fall disproportionately on low income households, particularly those that incur significantly higher and unavoidable energy bills due to their caring responsibilities. While we welcome the Programme for Government commitment to ensure carbon tax increases are progressive by spending €3m on targeted social welfare initiatives, we are concerned that the Fuel Allowance, which few carers receive, will be used as the main channel through which to target any offset. We are also concerned that Governments commitment in 2017 to “provide a financial support to persons with lifelong/long-term medical incontinence to help meet the cost of disposal of medical incontinence wear” has not yet materialised and as such we are calling for the urgent introduction of the scheme as part of Government’s ‘just transition’ commitments.

(vi). Carer’s perspective of the Assisted Decision-making (Capacity) Act 2015

Almost 5 years have passed since the Capacity Act received presidential assent. Described as a ‘ground breaking piece of legislation’, the signing into law of the Act was a significant milestone in Irish legal history and represents a triumph of autonomy by recognising that, as far as possible, all people have the right to live a life of their choosing and to play an active role in decisions about their personal welfare, property and affairs. While the Act is rightly focused on people with diminished capacity or those whose capacity may be called into question in the future – aka the ‘Relevant Person’ – there are many other groups of people who are relevant to the Act and to ensuring its principles are respected.

The following section sets out some of practical issues affecting one of these groups - family carers - the family members and friends who care for a person due to their illness, frailty, disability, a mental health difficulty or addiction and who are the most likely person to bring the legislation to life by assuming the role of a decision supporter or ‘intervenor’. The successful implementation of the Act is predicated on their willingness and ability to assume the various decision support roles legislated for and as such every effort should be made to consider their needs as we move towards full commencement of the Act.

The tensions and interdependencies of disability and care:

The tensions and interdependencies between the theoretical positions of giving and receiving care and more broadly disability and carer policy are well documented, however they have been brought into sharper relief with the ratification of the UNCRPD and the passing of the Capacity Act. While its introduction has been lauded, certain aspects of the Capacity Act are much debated in this regard, particularly Part 5 which legislates for court appointed Decision-Making Representatives (DMR), with some arguing that this form of ‘substitute decision making’ goes against the spirit of the Act and undermines individual autonomy. There is also a growing narrative with regard to the role of family carers with the suggestion that they can in some way disempower people with disabilities or obstruct their decision-making autonomy and an emerging aversion to the term ‘carer’ which is perceived to be based on unequal relationships characterised by emotion and dependency. While it is not our intention to pit carers and carer advocates against the disability movement, whose ambitions we fully endorse, we believe it is important to acknowledge this tension rather than ignore it. The reality is that once commenced, a significant number of family carers for adults with profound disabilities will have little choice but to take on the role of DMR unless they wish to see the role filled by a professional paid for by the State. Few would live the life of a family carer without an absolute commitment to the welfare of the person they are caring for and we believe that such carers should be supported and enabled to assume the role of DMR and that this should incorporate appropriate safeguards, for both the Relevant Person and the DMR.

Mind the Gap - transition arrangement for family carers:

The delay in commencing the Capacity Act, in particular Parts 3, 4 and 5, has created a legal quagmire whereby the protections it has legislated for (i.e. decision-making arrangements) are not yet available meaning carers have no legal status in terms of decision-making in the interim. At the same time passage of the Act involved highlighting, correctly, that next of kin and consent policies widely accepted heretofore have no legal basis. As a result, there has been a marked increase in Ward of Court applications as people seek legal certainty. This has created a situation entirely at odds with the principles of the Act and undermines the Relevant Person and their family who now have no mechanism through which to formalise the decision-making support required.

While *Family Carers Ireland* are eager to see the commencement of these parts of the Act, we are calling for interim measures to support their introduction. In our interpretation, the goodwill, custom and practice on which carers have traditionally relied when engaging with health professionals for example, will become illegal on the day that Part 5 is commenced. We estimate that at least 25,000 family carers will have to apply to the courts for a determination under the Act immediately on its commencement with no prospect of the system being able to cope with this surge. To avoid overburdening the court system we believe appropriate transitional arrangement for carers of people who require a DMR are needed, similar to the 3-year review period proposed in respect of the transfer of existing Wards of Court (c4,000 cases). Without such an initiative it is likely that an application will be made to injunct the commencement of the act on the basis that the delays in the court system are themselves a denial of the rights of both the person with disabilities and their family carers.

Providing practical support for decision supporters:

While the Relevant Person is at the heart of the Capacity Act, decision supporters are its cornerstone. These decision supporters will most often be family members, neighbours or friends who carry the normal responsibilities that life brings – work, family, education, home - but by virtue of ‘volunteering’ to act as an intervenor are accepting very considerable additional responsibilities. This is exacerbated for family carers who are also responsible for the care of their loved one, often on a fulltime basis. If family members and friends are to fulfil the demands required of decision supporters then it is critical that a range of measures are in place to support them, including dedicated training and information workshops, online resources, help line, information packs and for more complex cases the support of a dedicated key worker.

Resourcing the new system:

The Act outlines determination of capacity as a function of the Circuit Court. Family carers are unclear as to how the Circuit Court will make this determination or the costs involved. While the intention of the Act is to assist people to make their own decisions in so far as possible, there will inevitably be situations in which capacity will need to be assessed by an independent assessor or panel of experts. Section 50 provides that in making such a declaration the Circuit Court “shall have all such powers as are necessary to assist it” including directing the preparation of expert reports. It is unclear how this will work in practice given the very significant waiting times members of the public encounter when trying to access specialist health professionals. We have also experienced a reluctance from some medical professionals to complete the reports required for certain disability related social welfare schemes due the pressures they are under. The significant financial costs of obtaining appropriate medical reports must also be considered and assurances given that this burden will not fall to family carers to meet. In terms of the assessment of capacity itself, families have questioned the ability of an independent assessor or an expert panel to assess an individual’s capacity based on a desk review of medical reports and are calling for all assessments of capacity to incorporate a face to face assessment.

Achieving cultural change:

The saying that carers use not only their hands but their hearts and heads as well, captures the close emotional bond that often exists between a carer and the person for whom they care. As a

consequence, they find it particularly challenging to allow their loved one the freedom to make his or her own decisions, particularly when they deem those choices to be unwise. The realisation that they are not the default decision-maker for their loved one comes as a shock to many carers, who routinely make decisions on their behalf without understanding that they have no legal mandate to do so. The emotional impact of this, particularly on parents of adult children with a disability, is enormous, with some articulating feelings of being 'locked out' of their loved ones life, being undervalued and disregarded after many years of being actively involved in their decisions. Such is the intensity of these feelings that it is not unusual for a carer to become upset during discussions on this matter. Of particular concern to us is that the majority of family carers we engage with have little or no understanding of the Act or the implications it has on them or their loved one.

The magnitude of change required by the Capacity Act must not be viewed as only the concern of people with disabilities, their families, carers and health services, but rather will require a transformation in thinking across every aspect of society – within government, in homes, workplaces, hospitals, schools, colleges, banks, shops, restaurants, public transport etc. If we are to come close to achieving the ambitions set out in the Capacity Act then no individual, disabled or not, should be unaffected. The House of Lords Post Legislative Scrutiny Report on the UKs Mental Capacity Act found the Act has suffered from a lack of awareness and a lack of understanding and failed to achieve the cultural shift required, stating '*for many who are expected to comply with the Act it appears to be an optional add-on With prevailing cultures of paternalism and risk-aversion*'. The report also emphasises the '*lack of evidence of the use the Act in sectors including banking and policing*'. We must use the learning of our UK colleagues to better inform our practices and ensure we don't replicate the mistakes that were made.

Relational Autonomy – When a bad decision affects me!

A fundamental principle underpinning the Capacity Act is a person's right to make a decision even though others may think it unwise so long as they are deemed to have the capacity to make it. This raises important, but not uncontroversial, concerns by family carers who question what 'rights' they have if/when such decisions affect them. For example, in the case of a Relevant Person who chooses to spend much of their weekly disability payment on fast food, alcohol or cigarettes but has nothing left to contribute towards their living costs. This and similar scenarios are not uncommon in caring families. With a growing recognition of the relational aspects of autonomy – that people's identities, needs, interests and autonomy are shaped by their interpersonal relationships and mutual dependencies – what if any protections are to be afforded to families who are likely to be personally affected by unwise decisions?