

## Opening Statement for Health Committee

Thank you Chair and thank you all for having us here today.

Introductions if not already done – **Clare-Anne Magee, Head of Carers NI and Chair of the Coalition of Carers Organisations.**

Representing the Coalition and their own organisations I have with me today:

**Orla Watt, Director Parent Action CIC**

**Craig Harrison, Policy and Public Affairs Manager, Marie Curie**

**Valerie Sullivan, Chief Executive CAUSE**

You will have received a copy of the Coalition's recent statement on the experiences of carers during the pandemic and you will also have received a copy of Carers NI's report on their recent survey findings of current experiences of 761 carers in Northern Ireland.

A recent study shows there are now an estimated 320,000 carers in Northern Ireland. That's 320,000 who, since the beginning of this pandemic, have been providing practical, emotional and health care support to family members and friends, and we know that this figure is just the tip of the iceberg. This figure also doesn't include the upwards of 30,000 young carers estimated to be in Northern Ireland. There are countless people out there who don't see themselves as carers, just as a family member or friend, doing their bit to help out someone in need.

Everyone's caring journey is unique, and everyone will have experiences of caring during this pandemic which are slightly different, but whether you care for a partner with mental health issues, an elderly relative with dementia, a child with a Learning Disability or the countless other types of carer roles out there, there are some key issues that have surfaced throughout the course of this pandemic which will have both short and long term effects on the carer and the person they care for.

As lockdown began in the middle of March, the health and social care services (and Special schools), relied on by so many families, stopped overnight with little to no communication on when or even if they would start up again. Families were left without vital health therapies and practical support, or where that was available, it was greatly reduced.

Carers shielded with those they cared for who were considered vulnerable, they worried about care workers coming into their homes with no PPE, they feared for the person they cared for getting covid and ending up hospitalised... or worse.

Many carers struggled to adapt to working from home and caring fulltime, let alone adding home-schooling into the mix for those who had children too. Many young carers and young adult carers tried to balance online learning and worry over the uncertainty of whether or not exams were going ahead, with additional caring responsibilities.

Many who attended local support groups or activities had to try to come to terms with new technologies to enable them to continue to keep in touch with the outside world, sometimes that wasn't even an option for those living in rural communities or who didn't have access to digital technology.

And many feared for loved ones who were in hospital and care homes, unable to see them or provide the additional support that makes a real difference to the quality of care and of life in those homes.

Short breaks, surgeries and treatments were halted and many carers felt abandoned as services for the person they care for were re-directed leaving them holding the vast burden of care.

In the weeks and months that followed carers continued to struggle on as services and supports have been slow to restart. One carer commented to us recently:

*“I haven’t had an uninterrupted nights’ sleep in months and I am exhausted as I continually have to be alert to unpredictable and dangerous behaviour which has become more frequent and severe by lack of psychiatric and psychological care for several months as the Health Trusts simply stopped providing care and services”.*

Just last month, a report from Carers NI/Carers UK showed that:

85% of carers in Northern Ireland were providing more care now than they were pre-covid. The main reason for this increase in caring being because services (such as day centres/short break provisions) were closed or were greatly reduced.

Carers also cited that the increase in caring was due to the needs of the person they care for becoming more complex as a result of the restrictions and covid and because family and friends they relied on before for support were no longer available or able to help.

Almost two thirds of carers said they hadn’t had a break from caring, since before the pandemic despite many providing round the clock and more intense care than ever before.

73% of carers said they feel exhausted and worn out with almost half saying they feel they are at breaking point. It’s unsurprising then that two thirds of carers in Northern Ireland feel their mental health has worsened as a result of covid.

#### **Visibility of carers:**

Provided in people’s homes behind closed doors, the role of unpaid carers is largely unrecognised. Yet they provide high levels of care and support for the most vulnerable in our society.

This pandemic has seen a rise in the number of new carers and young carers coming forward in Northern Ireland.

Yet 7 months on from the beginning of this pandemic, they continue to feel they have been abandoned. That their voices and lived experience hasn’t been heard in delivery of services or in the reset and recovery process – carers must be part of the planning for the restoration of support services for those they care for.

#### **Isolation:**

For many in Northern Ireland, the first lockdown restrictions lifted back in July and some form of normality began to return for a few months at least, but this wasn’t the case for many carers as many continued, and still, continue to shield with the person they care for.

Carers feel cut-off and isolated with over two thirds feeling unable to keep in contact with neighbours, family members or the local community, and around half feeling lonely and cut off from people.

The mental health implications of this long-term are extremely concerning. Without access to appropriate emotional support, carers will be at greater risk of experiencing chronic stress, anxiety or depression.

## Access to Services

Many carers and family experiences are not consistent with the messages that services remain accessible.

## Carers Assessments

Despite being reassured that Carers Assessments would continue to be carried out, albeit virtually or over the phone, Department of Health data on Carers Assessments between April-June 2020<sup>1</sup> showed **that only 2789 Carers Assessments** were offered in what was the height of the first wave of covid.

This represents a 32% decrease on the number of assessments offered in the previous quarter and a decrease of 33% when compared to the same quarter of the previous year.

Of the assessments offered, 54% were accepted/carried out. This shows that where assessments were offered, more carers took up the assessment than we would normally have seen however, the problem was that not enough assessments were being offered in the first place.

The Quarterly Carers Statistics report highlights the impact of covid 19 on Carers Assessments and states that Carers Assessments were continued to be offered and completed “when requested” and that covid restrictions reduced the footfall in clients’ homes and therefore the “request” for Carers Assessments was reduced.

**Under the Carers and Direct Payments Act (2002)**<sup>2</sup> it is not the carers responsibility to “request” an assessment but rather the HSC Trusts “statutory duty to inform” carers of their right to have an assessment.

The Quarterly report also states “direct contact was maintained by telephone at an increased level, however, **the administration of information gathering work, such as that for Carers’ Assessments, was not prioritised in operational services during the pandemic**”.

Many carers we have spoken to, across our organisations, say they have had no (or very little) contact with their social worker or key worker over this period and despite many attempts to contact them, have had difficulty reaching them or have been “triaged” by student social workers with no particular authority to support them.

## Day centre/Schools etc closure

The closure of day centres, special schools and short break provisions and the limitations in many domiciliary care packages has had a detrimental effect on the person in need of those services but also on the carer and the family who are picking up the pieces.

Loss of attendance at school/day centres is already having an impact for children and adults with learning difficulties and/or learning disabilities who find change difficult and whose developmental progress has been delayed as a result of the closures and reductions and, ultimately, whose mental health has been affected by lockdown as a result. My colleague Orla from Parent Action will be happy to take questions on this later.

Similarly, the delivery of mental health services has changed considerably during the crisis, lockdown and social distancing measures have halted many face-to-face services and in-patient care. However, mental health services at a community level, while also critically impacted, appear to have been able to adapt more quickly and Valerie can speak to this later.

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<sup>1</sup> Quarterly Carers Statistics for Northern Ireland April-June 2020 (DoH Sept 2020)

<sup>2</sup> Carers and Direct Payments Act

Over a third of carers said their own NHS treatment has been delayed as a result of covid whilst over half said treatment for the person they care for has been delayed, both of which has affected individual health and wellbeing.

Whilst we acknowledge the difficulty in re-opening services and restarting treatments, due to the risk of infection for both staff and attendees etc the longer-term impact of keeping these services closed or at the current level of reduced capacity could be much greater.

### **Direct Payments**

Concerns have also been raised by some carers about the lack of awareness and flexibility around the use of Direct Payments as a means to buy-in supports/services.

Despite Department of Health guidance on the “flexibility” of Direct Payments, carers are telling us that the approaches by different Health and Social Care Trusts, different programmes of care and indeed, between different social workers is causing huge inconsistencies with some being more flexible than others.

This caused huge concern for many carers at the beginning of the first lockdown whose PA’s were shielding or self-isolating and carers had no one else to support them.

Some carers sought to use their direct payment budgets to employ family members to help them and more often than not, these requests were refused by the Trusts leaving carers to struggle on for weeks and months on their own.

### **Balancing work and care**

The majority of carers who responded to the recent Carers NI/Carers UK survey were balancing work and caring responsibilities. Some were retired or looking after dependants full-time and 4% said their ability to work is limited because of insufficient social care support.

Of those who were working 37% were key workers working to keep society functioning through our key services, and 47% were working from home. 9% had to reduce their working hours because of caring responsibilities during covid whilst 4% had to give up work because of caring.

For those who are juggling work and care we need to see more support from employers to help them continue to provide care and work but we also need a reliable social care system to enable them to do that .

### **Young carers**

Young Carers are often an invisible group who provide pivotal support relating to health and social care within their household. Through Covid 19, young carers found that their caring role increased because of being in the home all day and, in a sense, there was no escape from this caring role and responsibilities.

They often lost their whole routine and by not attending school nor being able to attend face to face meetings and activities with support networks like Action For Children- this dealt a big blow to their emotional wellbeing. Add that to their ongoing anxieties in terms of returning to school if they are caring for family members with vulnerabilities. Often the support they receive from schools is variable as there is a major gap in terms of understanding their situation amongst staff at school, or within the wider community.

## **Loss Grief and Bereavement**

The COVID-19 pandemic has torn up the rule book when it comes to loss, grief and bereavement, and carers are one of the groups bearing the brunt of that. Many carers have been shouldering an extra end of life care burden at home and dealing with their own feelings of loss and grief without access to their support networks.

Carers have been heavily impacted by the disruption that COVID has caused to the community and family rituals that normally follow a death. They haven't been able to rely on their wider family network 'rallying around' them, and events that would usually facilitate collective support and remembrance – like funerals and wakes – have had to change fundamentally.

What this means is that, during the moment when they are perhaps at their most vulnerable, carers have been deprived of the family and community support that we would all have taken for granted only a year ago. In the worst cases, they may be facing the grieving process entirely alone, and this loneliness can make grief much more intense and harder to process.

Responding to this situation involves many different components, but one key aspect is ensuring bereaved carers have access to timely and high-quality bereavement support. The picture here is complicated, because demand for those services was outstripping supply even before COVID-19 came to our shores. We need investment and training to boost capacity in this sector, and Craig would be happy to talk more about this during the Q&A.

### **So what needs to happen next?**

The majority of adults in Northern Ireland will care for a family member or friend at some point in their lives,<sup>3</sup> but the impact on their health, finances and wellbeing is often underestimated. Even a few hours of care a week can have a significant impact on carers' lives, yet there are thousands of people caring around the clock. During this pandemic many have cared without access to any form of break.

Whilst we understand many health and social care staff were isolating or were re-deployed to front-line services and that daycentres/short break provisions can only be opened safely and at minimum risk to staff and those attending etc, carers are hugely frustrated that their services and supports have not been protected at a time when they needed them most.

**Government must prioritise carers in its plans, carry out an urgent review of breaks' services and ensure that wider social care services have enough funding to manage over winter.**

Whilst much has been done to rightly recognise the work of health and social care professionals in this pandemic, the role unpaid carers have played in the effort against COVID-19 is often forgotten.

Many carers feel invisible and unrecognised for all that they do. With the recent increases in local lockdowns, carers will be continuing to provide high levels of care through the winter months. It is only fair that they are recognised for the invaluable role they play in the national effort at this

time, but also that they receive the right support. It's easy to see why carers feel they've been abandoned and left to cope with everything alone.

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<sup>3</sup> Carers UK (2019) 'Will I care?'

Carers are worried about their ability to continue to provide care over the winter and through the rest of this pandemic without more supports in place for both them, and the person they care for.

In the short term, we need to see:

- The quick and safe reopening of daycentres/short break provisions. Ultimately, if treatments and services for people with disabilities, mental health issues etc are re-introduced then some of the burden on carers will be lifted.
- Carers need to be involved in the planning of reopening of services and as part of the wider reset and recovery plans. Co-production and true partnership working with carers to restore essential services which supports them to transition back to some form of normality as lockdown eases and while covid 19 remains present
- We need therapeutic interventions for carers to support their mental health and emotional wellbeing so that, if they choose to, they can continue to provide care
- Cross Departmental working to support carers is vital at this time. Whilst carers generally sit under the umbrella of Health they are involved in every aspect of our society from being part of the wider workforce to reaching their full potential through our education system. We need to see the Department of Health working collaboratively with other Departments including the Department for Communities, to address the financial impact caring during covid is having on household finances; the Department of Education to support our young carers and the children and young people within our education system who have additional needs and who are not being fully supported at this time; and with the Department for the Economy to help employers better support their workforce who are trying to juggle work and caring responsibilities.
- More needs to be done to ensure carers/family members have access to relatives in care homes, particularly at end-of-life and that those bereaved during the pandemic are supported to deal with their grief
- We need to see increased offers and uptake of carers assessments through Health and Social Care workforce training and wider public promotion of caring and carers assessments.

Contingency planning is key to the assessment process and should be encouraged widely so that if something happens to the main carer, a plan is in place to support the person being cared for.

Many of these issues have always been around for carers but covid has hugely exacerbated them and has shone an even bigger light on the vital role carers play in our society. They are undoubtedly the backbone that holds the health and social care system in Northern Ireland together.

Therefore, longer term, we need to see:

- New legislation to protect and enhance the rights of carers in Northern Ireland, developed with carers, as per the Power to People Report (2017)
- We need a new cross-departmental Carers Strategy to replace the 2006 strategy and we need ringfenced funding to ensure the outcomes of this can fully be achieved
- With more and more carers struggling to make ends meet, we need to see increased financial support for carers in the form of Supplementary Payments or similar
- We need to work with employers to support carers to remain in work and return to work
- And we need greater support for our young carers to ensure they have a life of their own and that they can reach their full potential

The COVID-19 pandemic continues to have a monumental impact on unpaid carers' lives – not only because of the increased amount of care that many are having to provide, but because of the far-reaching effect that providing this care is having on many aspects of their life; their relationships, their mental and physical health, their paid work and their emotional wellbeing.

Whilst there have been positive innovations in tech-based support for carers and some carers have greatly enjoyed the slower pace of life due to the COVID-19 pandemic, the vast majority have found life significantly more difficult.

Winter is fast approaching, bringing with it colder weather and the usual pressures on health services. Worrying about the coming winter period is causing stress and anxiety for carers, many of whom have had no break from caring for many months and are reaching breaking point. The risk of burnout is especially concerning when so many carers are worried that there is no back-up or contingency support available for the people they care for, should they get ill.

It is important to remember that unpaid carers are just as vital in the national effort to keep those with complex health conditions and disabilities safe during this outbreak and beyond.

Thank you for your time this morning and we would be happy to take any questions at this point.