

A Bill of Rights for NI?

Carers NI Consultation response

February 2021

Background

Without carers, Northern Ireland's health and social care system would completely fall apart. As our population ages and people live longer with illness and disability, carers are becoming more and more important to keeping our loved ones well and easing the pressure of a collapsing health and social care system. We have seen first-hand throughout the Covid-19 pandemic just how much family members and friends have stepped in to protect the most vulnerable in our society. And we have witnessed the devastating impact this has had on them.

Far too many carers are stretched to the limit looking after loved ones, while also having to worry about making ends meet. We want a world where carers are supported not only to cope with the challenges of looking after someone, but to build a life of our own too. A life which includes caring but is not overwhelmed by it. This matters to all of us. At some point, we will all care for family or friends who are older, ill or disabled, or we will need that care ourselves. At that point, we will realise how important it is to make a better world for carers. For there is nothing more human than looking after loved ones, and no more pressing social issue than making that care possible.

Carers NI are here to make life better for carers. Working as part of Carers UK, we give expert advice, information and support to carers across NI. We connect carers so no-one has to care alone, we campaign together for lasting change and we innovate to find new ways to reach and support carers. Our key strategic priorities are to battle for greater understanding of carers and support for carers in our society, be there for carers with information and advice from the start and build a network of carer positive employers.

Summary

There are many circumstances in Northern Ireland in which different individuals will have greater or lesser access and enjoyment of certain rights due to a range of circumstances and factors.

We do not believe that everyone in Northern Ireland enjoys the same basic Human Rights and therefore wish to see the introduction of a Bill of Rights here so that those who are vulnerable or who are caring

for someone who is vulnerable, have a safety net to fall back on when their rights or access to rights have been denied.

We estimate that there are over 300,000¹ carers in NI looking after a family member or friend (unpaid) who is ill, elderly or has a disability. We hear from them every day about the lack of access to basic practical supports, health and social care, education, employment, social security etc for both themselves and the people they care for. Whilst caring can be a hugely rewarding experience it can also be exhausting and overwhelming.

Specific legislation to support carers in Northern Ireland is extremely limited and whilst carers rights have been a long-standing issue often pushed to the background, during the covid-19 pandemic, the impact of those rights not being met has led to 85%² of carers here providing more care now than pre-covid. This has had a detrimental impact on the lives of carers and those they care for. Our recent Caring Behind Closed Doors report (NI)³ showed that the closure of day centres, short break provisions, special schools and other support services left almost two thirds of carers here without a break for over 9 months. It also showed that the impact of this extra caring role (sometimes on top of trying to balance home schooling, work and other responsibilities) meant that around 60-65% of carers felt their physical and mental health had worsened over the first 9 months of the pandemic.

In 2014, The Human Rights Commission NI produced a report highlighting the Human Rights of Carers⁴ and made a series of 15 recommendations in order to improve the rights of carers here. Seven years on, and a global pandemic later, carers rights in Northern Ireland have moved on very little, if anything, they have taken a few steps further backwards. We believe that family carers need more protections for their human rights.

Carers Rights

Right to Family Life

Many carers are unable to have a life outside of caring. Whether their caring role requires 24/7 hands-on practical and emotional support or whether they're trying to balance caring with other responsibilities such as childcare or work, carers are often too busy, exhausted or stressed to have much, if any, of what society sees as a "normal" family life. The additional tasks required of carers, whether they're caring for an elderly relative or a child with a disability include so much more than what "normal" family life has to offer. Hospital visits, administering medication, arranging domiciliary care packages, co-ordinating GP appointments, providing emotional support every day of their lives to those most vulnerable etc. It can often mean that others within the family can feel left behind which can lead to resentment and

¹ Carers Week report (June 2020) Carers UK

² Caring Behind Closed Doors (Oct 2020), Carers NI

³ Caring Behind Closed Doors (Oct 2020), Carers NI

⁴ The Human Rights of Carers in NI (2014), NIHRC

relationship breakdown, or they too can also take on a caring role (such as in the case of young carers) and it often begs the question, “where does family start and caring begin?”

Right to adequate standard of living and the Right to Social Security

Research has demonstrated that caring responsibilities can have negative implications on an individual’s ability to maintain an adequate standard of living. Providing care often involves a significant financial commitment whether that’s the cost of keeping the heating or electrical medical equipment on 24/7; paying for public transport or extra diesel to attend regular hospital appointments or for some, whose caring role is so immense that they have to leave employment in order to continue to provide care, taking a significant drop in household income which is not fully picked up through the social security system.

In a recent survey of over 760 carers in NI, only 54% of carers here said they were able to afford their bills without struggling⁵. Furthermore, 28% said they were struggling to make ends meet and 9% claimed they have been in debt as a result of their caring role.

Carers Allowance, the main benefit to carers, has a very strict eligibility criteria meaning only around 50,000 carers in NI receive it. At the moment, Carers Allowance is currently £67.25 per week (2020/21 rate). Based on the average carer providing care for 35 hours per week this equates to just £1.92 per hour. It is the lowest benefit of its kind and in no way reflects the contribution carers make saving the NI state £19 million every day of the Covid-19 pandemic⁶

With Carers Allowance only set to rise by 35p from April we believe this rate in no way supports carers to have an adequate standard of living. Many carers are unable to access employment due to the nature of their caring role and are therefore reliant solely on Carers Allowance and Universal Credit to survive.

We also echo calls made by Marie Curie NI to include a right for all terminally ill people in NI to access the social security support they need without bias or discriminatory outcomes based on estimations of their life expectancy (under the Special Rules on Terminal Illness) so that they and their families are not overburdened at a time when end-of-life care and support are needed most.

Right to Work

Pre-covid 19, 15% of the Northern Ireland workforce were juggling work and care. Since the pandemic, there has been a significant rise in the number of people juggling work and care, estimated to be as much as 26% of all carers here⁷. Of those who have started providing care as a result of Covid-19, almost two-thirds are in employment. The majority of these new working carers are women. We know women are disproportionately affected by caring roles but as a result of Covid-19, more and more women are having to choose to leave work (or reduce hours, or be furloughed) as a result of their caring role.

⁵ Caring Behind Closed Doors (Oct 2020) Carers NI

⁶ Unseen and Undervalued (Nov 2020) Carers UK

⁷ Making Caring Visible (June 2020) Carers UK

Covid-19 aside, carers have always had difficulties in accessing employment that fits around their caring role and the social care package they may have been attributed (or not in some cases). Until employers begin to become more “carer friendly” by introducing the likes of flexible working from day 1, Carers leave, employer support for caring etc, carers will continue to have unequal access to the labour market.

Right to Education

There are an estimated 8000+ young carers and young adult carers Northern Ireland who might have the same right to access education as every other young person here however their caring role at home will disproportionately impact on their ability to enjoy or realise that right eg caring may lead to poor attendance and performance in school; distractions with worrying about what’s happening at home; extra travelling if studying away from home and distance caring etc.

Right to Health

The Carers and Direct Payments Act 2002 is one of the few pieces of legislation that offers protections to carers in Northern Ireland. It gives carers the right to a separate assessment of their needs and places an obligation on Health and Social Care Trusts to identify and provide information to carers. All carers providing or intending to provide care on a regular and substantial basis therefore have a legal right to have their needs assessed. The legislation also requires that this Assessment is reviewed each year or sooner if the needs of the person being cared for deteriorates.

Research from our State of Caring report in 2019 showed that around a quarter of carers had received an Assessment in the previous 12 months. Many carers we speak to have never been offered or even heard about a Carers Assessment, despite providing care for many years.

Monitoring on Carers Assessments is collected quarterly by the Health and Social Care Trusts and published by the Department of Health. Despite Census data from 2011 saying there are around 214,000 carers in Northern Ireland, just under 18,000 Carers Assessments were offered in 2018/19, 16,000 in 19/20 and in the 6 months between Apr-Sept 2020 (during the height of the pandemic) just under 6,200 Carers Assessments were offered⁸. The Carers Assessment is one of the main ways carers can talk about the impact of caring and what they feel they might need in order to continue to provide that care and unfortunately, not all carers are being offered it. Even where carers do get offered the Carers Assessment and complete it, whilst every effort is made by the Health and Social Care Trusts to deliver on the resulting action plan, there is no statutory duty on the Trusts to deliver. Unmet need is therefore a major issue for many carers which is not being picked up effectively by the Trusts.

With the Covid-19 pandemic closing day centres, short break provisions, schools etc and the significant reduction in the provision and capacity of domiciliary care provision, it’s no surprise that our Caring Behind Closed Doors survey showed that 85% of carers here were providing more support now than they were pre-covid and that over 60% had not had a break from caring during the pandemic. This resulted in

⁸ Quarterly Carers Assessment statistics (Sept 2020) Dept of Health NI

65% of carers here saying their mental health had worsened and 60% saying their physical health had worsened as a result of the closure of services and reduction in short breaks and supports they received during covid. Almost three quarters of carers were exhausted and worn out with around half at breaking point.

Even now, despite carers finally being acknowledged in the JCVI priority groups for the covid vaccination, carers are still left in limbo as to how and when they will be called forward to access this vital lifeline that is much needed as the main provider of care for the most vulnerable in our society.

When we consulted with carers on this consultation some also felt there was also a need to a right to social care, distinct but complementary to the right to health which might be worth considering when developing a new Bill of Rights.

Right to participation

The role of those caring for a person with a disability in supporting them to take decisions is recognised within Article 12 of the UNCRC and the involvement of family carers in the planning and delivery of services and supports is also recognised within the Health and Social Care Reform Act (NI)⁹. Carers have told us that all too often, this participation and involvement is not happening and that they often feel “shut out” from decision-making despite having a wealth of knowledge and experience in relation to the care and the needs of those they are caring for. Carers have reported¹⁰ that they feel ignored by the health and social care system and where they have been included in decision-making processes it was in the context of the person that was being cared for rather than themselves as people with their own rights

The NIHRC found that¹¹ by empowering and including carers in decision-making, decisions would lead to more positive outcomes for all.

Section 75

Carers are afforded some protections within section 75 of the Northern Ireland Act (1998) as “persons with dependents” however, there are some grey areas within this and there remains a lack of awareness of their inclusion in this category. Worthy to note that within your own consultation survey those “with caring responsibilities” are mentioned but that in itself could include parents and/or carers, both perhaps deserving of separate bullet points.

The NIHRC¹² noted the lack of clarity on the inclusion of carers in the section 75 protected categories and recommended guidance be issued to the NI Executive departments to ensure that the rights of carers are appropriately considered.

⁹ Health and Social Care Reform (NI) Act 2009

¹⁰ The Human Rights of Carers (2014) NIHRC

¹¹ The Human Rights of Carers (2014) NIHRC

¹² The Human Rights of Carers (2014) NIHRC

We would advocate for carers to be an explicit protected characteristic within this grouping however, at the very least, a Bill of Rights that was robust enough to protect carers from discrimination, would be a good start.

The Equality Commission NI report in 2012¹³ also notes that existing disability equality legislation which includes a call for express protection against “associative discrimination” which is in statute in Great Britain under the Equality Act 2010, but is not yet in equality law in Northern Ireland. Carers could greatly benefit and be protected if this was included in NI law.

Conclusion

In 2016/17, a review of Adult Social Care in NI took place and the resulting Power to People report recommended that the rights of carers here be put on a legal footing and that legislation to protect and support carers should be brought forward. 4 years on from the publication of that report and carers are still waiting.

We believe a realistic and achievable Bill of Rights in Northern Ireland, based on values of human dignity, fairness, mutual respect, accountability and transparency that supported carers in their everyday caring roles would be one way of ensuring carers rights here were protected.

The intersectionality of carers often means that carers can fall into a number of different categories each with unequal access to some of the rights afforded to most of us. For example, some will be older carers, female, working perhaps with a disability themselves which gives even more inequality to their circumstances. It is important that in the development of any Bill of Rights we are mindful that as humans, we are not all just one thing, we are many things, connected to each other and the world around us, yet unique. A Bill of Rights is needed to provide the safety net we all require and it needs to be reflective of our society, flexible enough to meet the demands of our individuals and our society as it grows.

¹³ Strengthening Protection for Disabled people (March 2012) Equality Commission NI

Contact us

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