

## Speech: Carers' Act 10 years on, care and human rights

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### Welcome and introduction

Good morning.

Thank you for the welcome and for the invitation to be here today.

It's a real privilege to join you today and reflect with you on the right to care – or not, and the rights to be cared for.

Before I begin, let me say a few words about who I am and the organisation I represent.

I am Professor Angela O'Hagan, and I am the Chair of the Scottish Human Rights Commission. We are Scotland's independent National Human Rights Institution - sometimes described as the country's human rights watchdog.

Our role is to work alongside people to understand whether and how their rights are being realised. We seek to amplify those voices, and to hold duty bearers to account for meeting their human rights obligations.

A core part of our mandate is to promote awareness of rights, and to support both rights holders and duty bearers to understand what those rights mean in practice.

### Reflecting on care

Care happens in homes, in communities, and in relationships.

It shapes how people live, day to day. It shapes what people are able to do, and what becomes possible for them. It touches all of our lives, in one way or another.

Most care is provided by women, to whom the 'burden' of care usually falls due a series of inter-connected, gendered, established social structures whereby women are expected to be 'carers', the undervaluing of women's work and income and the parallel undervaluing of the provision of care mean that women are more economically expendable in fulfilling the provision of care which is also assumed to be of no or little economic value.

When care is discussed in the media or in policy discussions, it tends to be talked about in a very particular way.

We talk about cost, about capacity, about service delivery.

And of course, these things matter.

But there is more to the story. The way we frame the story affects how we make decisions and how it plays out in everyday life.

Because the way we describe care shapes policy decisions and funding priorities. And it shapes how the public understands what care is, and what it is for.

At the moment, there is still no broad social consciousness about the fundamental nature and character of care. Something that is so fundamental to our lives often remains politically invisible.

And because of that, carers and the provision of care too often remain separate from central, or so-called 'mainstream', policy decisions.

## A different story

Today, I want to suggest a different way of telling that story; a story that places care firmly within a human rights framework, and is a story about people.

Our Strategic Plan has one phrase which for me is our touchstone: human rights are about recognising the humanity of the person standing beside you. In caring, we must recognise the humanity and the rights of people receiving care, disabled people, older people, people with long-term conditions; and those providing care. Those commissioning/procuring care services with public funds are bound by human rights legal obligations, as well as key principles which I will come on to, but which include non-discrimination, no rolling back on existing provisions, and ensuring that at the very least the 'minimum core obligations', that basic floor of dignity and respect for people is upheld.

Because while social care may not always be named explicitly as a standalone right, it plays a central role in how many fundamental human rights are realised.

Human rights conceptually and as legal frameworks set minimum expectations. They provide a floor, not a ceiling. They establish what people should be able to rely on. When we apply that thinking to care, we begin to see clearly what is at stake.

Being able to remain in your own home.

Maintaining relationships.

Living with dignity, and with a sense of routine and normality.

These are not abstract ideals. They are basic conditions of living a life with dignity.

The legal framing protecting these rights includes:

1. Carers (Scotland) Act 2016, which we are here to discuss today, provides legal rights for carers, including adult carer support plans, young carer statements, and access to information, advice, and support services. The 2016 Act recognises the vital role of unpaid carers and aims to ensure they can access the support they need to maintain their wellbeing and continue caring effectively. The Act came into force on 1 April 2018 and applies to all carers in Scotland, regardless of the number of hours they provide care for.
2. Human Rights Act 1998
3. Social Care (Self-directed Support) (Scotland) Act 2013: Provides individuals with choice and control over their care.
4. Adult Support and Protection (Scotland) Act 2007: Aims to protect adults at risk from harm.
5. Public Bodies (Joint Working) (Scotland) Act 2014: Integrates health and social care services to improve outcomes.
6. United Nations Convention on the Rights of the Child (UNCRC): covers all aspects of a child's life and sets out the civil, political, economic, social and cultural rights that all children everywhere are entitled to.

7. The Convention on the Rights of Persons with Disabilities (UNCRPD) sets out a number of principles (such as dignity, autonomy and participation) for social care frameworks, as well as the design and delivery of services.
8. European Convention on Human Rights:
9. Article 3 (freedom from inhuman and degrading treatment)
10. Article 5 (the right to liberty and security)
11. Article 8 (the right to family and private life) under the Human Rights Act.
12. Article 12 (equal recognition before the law)
13. Article 19 (the right to independent living) means protecting the rights of disabled people to live and participate in the community and giving them the same choices as non-disabled people.

## A story based on rights

A rights-based system is one where people can access services, afford them, rely on them, and shape them around their lives. It is a system grounded in universality, moving beyond variability or postcode differences.

At its core, it begins and ends with recognising the humanity of the person standing beside you. Three principles are particularly important here.

The first is non-discrimination. Non-discrimination means that these rights belong to everyone. They are universal. Our rights to dignity, to family life, to freedom of religion, and to the highest attainable standard of health remain intact regardless of age, disability, race, or any other difference. If we have to rely on care, those rights must remain intact. And in fact, disabled people have specific rights as a protected group under the UN Convention on the Rights of Persons with Disabilities.

The second is non-retrogression: the idea that the Government's policies and legislation should not roll back on what has already been achieved. A struggling economy and the cuts that too often go along with it should never mean that people have less rights tomorrow than they did in the past. Maximising available resources for the progressive realisation of rights is an obligation of governments and public bodies, so while there may never be enough money, limited resources is not a reason for not operationalising rights in practice.

Equally important is participation. A human rights-based approach means that people are actively involved in decisions about their care, about services, and about the future design of the system. It means paying attention to who is recognised, who participates, and whose voice is heard.

But I want to pause to consider something else related to participation and voice, particularly thinking about carers, people receiving care. Do we use the language of rights in our everyday lives? Or do we sometimes hesitate? How do people in receipt of care services use the language of rights? Are they encouraged to or is that frowned upon or rejected.

Do we worry that if we speak about rights, we might appear difficult, or disruptive. or that it might affect the care our loved ones receive, or the relationships we rely on? I think we can, and we should, use the language of rights in the everyday.

Because what we are asking for is not extraordinary. We are asking for the legal minimum: for dignity, for respect, for the basic conditions of a decent life. And that idea of a minimum is built into human rights law itself. International human rights frameworks place a duty on public authorities to meet minimum core obligations, and to use the maximum available resources to progressively realise those rights.

## Human rights and care

When we think about rights in care, we need to think about all the people across the system. Independent care providers have an important role to play.

Public bodies act as duty bearers, responsible for realising rights: for the people they support, for the workforce employed, and for their families.

And what is important is that these roles are interconnected. At different points in our lives, many of us will move between them.

We may receive care. We may provide it, unpaid, within our families or we may work within the care sector. Care helps make rights meaningful in everyday life.

Good quality care is a gateway to so many rights.

Without that support, independent living becomes difficult, health deteriorates and our opportunities to participate in society diminish.

Without care and support, rights to dignity, to health, and to participation cannot be realised in practice.

And so human rights are not separate from care. They are central to how care is provided. At the same time, we know that the realisation of these rights remains uneven, and in many cases, inadequate.

## Rights and care in practice

When we think about economic, social and cultural rights, we are talking about the things required to live with dignity.

The highest attainable standard of health, adequate housing, access to cultural life. These are the everyday rights that make life worth living. These are the rights in focus in what, we hope, will be a Human Rights Bill coming forward in year two of this parliamentary session, incorporating Economic, Social, and Cultural Rights into law in Scotland, making it possible for people to claim their rights in the Scottish legal system.

Currently across Scotland, we see challenges in accessing services and achieving adequate standards of living. There are gaps in access, affordability and availability including, as we have learned through our SHRC local monitoring work, in the rural and island communities of the Highlands and Islands, and most recently across the South of Scotland. Sadly, as we build our evidence base on how rights are being experienced across Scotland, we are learning that too often, people are being denied their rights.

Our work on 'deinstitutionalisation' has exposed the slow progress towards enabling people to live independently. Our Tick Tock Spotlight on Article 19 (CRPD) and the right to independent living has exposed the slow progress towards implementing 'Coming Home' and to put an end to the horrendous practices of people with severe learning disabilities and/or who are autistic being deprived of their rights and liberty by being kept in institutions, without medical need.

We have seen continuing inappropriate placements, people with learning disabilities or autistic people kept in hospital without medical need. We have seen a gap between commitment and practice, a lack of clarity on spending, and a sense that the care and rights of disabled people are not being prioritised. These are real, lived failures of human rights. And it is our role to bring those realities to light, to build evidence, and to put that evidence before those in power.

We are also working to improve access to justice when rights are not realised. A key focus of our work for the next year will be a spotlight on the experiences of people who make complaints about social care. Too often, people in Scotland are experiencing human rights denials and facing barriers that prevent them from accessing justice. Complaints processes need to be clear and easy to use for service users, and are a very important source of learning for service providers.

The journey to access justice for human rights breaches can be long, complicated, and expensive, requiring rights holders to have knowledge about where to turn for help, money for and access to specialist legal advice and the time and emotional resilience to pursue complaints.

Our social care system should be grounded in human rights, and it should be easy to access justice when that does not happen.

## Care as the backbone of our economy

I also want to talk about care as part of our economic infrastructure, which has been an area of my work for many years. Because every part of our economy rests, in part, on the work of care, both paid and unpaid.

In Scotland, around 1 in 25 people receive social care. Around 1 in 12 jobs are in care. A disproportionate number of workers are “new Scots”: migrant workers making an invaluable contribution.

These are skilled, relational, complex roles. The rights of these invaluable workers matter. Their pay, conditions, and job security should matter to all of us.

Around 80% of the workforce are women, often in part-time roles, often managing a double burden of paid work and caring responsibilities at home.

And beyond that, unpaid care represents a vast and often invisible contribution, again disproportionately carried by women. This is difficult to measure, but it's estimated that between half and three quarters of all unpaid carers are women.

This labour is essential. It supports individuals to live with dignity. But it also enables people to work, families to manage responsibilities and communities to sustain themselves. Economic participation depends on care. Paid care sustains employment within the sector and beyond it. Unpaid care underpins everything

Care does not exist in isolation. It is connected to housing, to social security and poverty and to the health system. And when pressure builds in one part of the system, it moves across to another. Often, it is care that absorbs that pressure.

## Rights-based public spending

And yet, care is still not fully recognised in economic policy. It is not always reflected in investment decisions. That must change.

Care must be visible in economic thinking and in budget decisions. Because ultimately, public spending is one of the most powerful tools we have to realise human rights.

Budgets reflect priorities. The way resources are allocated shapes outcomes. And those choices matter, for the quality of care and for rights realisation.

A human rights approach to budgeting means linking resources directly to needs, to outcomes, and to rights. And the same applies to public procurement. When a public body contracts with an independent care provider, human rights should form the basis of that contract, ensuring that rights will be respected, protected and fulfilled in how that public contract with public money is conducted.

Procurement is not just a technical process. It is about how responsibility for rights is shared. And in that system, you as independent providers, are acting as guardians of those rights.

## Conclusion

So let me close by returning to where I began.

A human rights-based approach reframes care. It tells us that care is about duty, obligation, and legal protection. But it is also about humanity, about recognising the inherent value of every person.

Care is at the heart of rights and human rights must underpin care.

Specifically,

- Context of care as a right – and the right not to care
- Carers have rights but carers' rights (to privacy and family life, income/social security, decent housing, etc.) across the framework are

impacted by being carers, especially long-term carers and within that, particularly women from further marginalised groups

- Care is a key pillar of our economy yet carers lose out financially, and care is not valued or resourced – hence a Human Rights Budgeting approach is essential
- Human rights provide a framework for service design, delivery, and outcomes
- Public service reform may be motivated by fiscal constraints, but human rights have to provide not only the value base but the framework for service and structural design and delivery
- A human rights based approach should be embraced as a way of ‘thinking and doing’ in public service design and delivery, providing a way for budget holders and service managers to respect, protect and fulfil individuals’ rights
- People are being squeezed by reductions in care services, public resources and the increases in cost of living. Our Spotlights on Poverty and on ESC Rights across Scotland highlight the impact on carers, the distance people are from their rights and entitlements as well as the distance from decision making and power
- 10 years on from the provisions of the Carers’ Act, there is an implementation gap which a human rights based approach can bridge
- With a commitment to human rights realisation, the ambition of unpaid carers and the care workforce being equal partners in care can be a more realistic ambition, part of our intention too in our focus on human rights based social care complaints, and our human rights defenders toolkit that flowed from the Tick-Tock project and approach.

Thank you.