











20 November 2024

An open letter from the Disabled People's Movement

## The National Care Service; If not now, when?

The signatories to this letter are leaders within the Disabled People's Movement in Scotland (the Movement). We are disabled people, and we represent disabled people across Scotland. We know the stark reality of disabled people's lives and the urgent issues that must be addressed - not least social care.

We are truly shocked to hear reports that the National Care Service will be delayed or scrapped altogether. This cannot be allowed to happen when wholesale reform is so urgently needed.

The current social care system frequently fails to meet our needs or uphold our human rights and dignity; that is, if we get it in the first place. For too long, disabled people have been the objects of services, not the subjects of our destinies.

Despite our attempts to talk to COSLA, they have not listened to us. We have also been shut out of some local Integrated Joint Boards across Scotland, e.g. in Glasgow where members of the Glasgow Disability Alliance (constituting over 5,000 disabled citizens of that city) have been ignored when pleading with the IJB not to cut the social care budget which undermines early intervention and signals a return to institutional care if this is seen to be a cheaper option.

COSLA, the Unions, Local Authorities and political parties have buried their heads in the sand, withdrawing their support for the National Care Service Bill: offering no alternative proposals.

The National Care Service was meant to be a much-needed reform, which would raise standards, end the postcode lottery, fully implement Self-directed Support, ensure accountability to the service-user, as well as the electorate, and properly value unpaid carers and the workforce. It would be based on human rights and include the involvement of those who received its services in its decision-making at all levels. By far, disabled people are the highest users of social care and therefore should be at the heart of plans to strengthen and transform the system.

In reality our voices have been diluted, and the need for change – previously agreed by all stakeholders including political parties, Unions, COSLA and Local Authorities - has been forgotten.

Now, the National Care Service has become a political tug-of-war between the Scottish and Local Governments about who should have the responsibility for social care, rather than how to meet that responsibility.

The Movement and its members, alongside the third sector and carers have invested huge amounts of time, energy and emotion in trying to develop a truly participative and positive National Care Service; one which will value the user as well as the workforce; one which will be the envy of the UK and the world. This must not be wasted.

As we wait for reform, members of our Movement are reporting that they cannot get washed, dressed, go to the toilet or eat because they cannot get the social care support they need. But it is not only these basic tasks for which social care is so badly needed, it's their ability to live a purposeful life, within their family and community-at-large. Even for those who do get social care, they are charged exorbitant fees, which plunge them further into poverty.

This is why we need a National Care Service and fundamental reforms to the broken systems. Disabled people of all ages need change, and the status quo is not an option because disabled people are suffering. We need vital support to live a life of dignity and choices that non-disabled people take for granted. We must remember that this lived experience was the driving factor that led Ministers to commission the Independent Review of Adult Social Care (2021).

The whole impetus for a National Care Service came from this Review. It saw this new system enabling;

"Everyone in Scotland (to) get the social care support they need to live their lives as they choose and to be active citizens. We will all work together to promote and ensure human rights, wellbeing, independent living and equity."

In his foreword, the Review's author Derek Feeley wrote:

"... the story of adult social care support in Scotland is one of unrealised potential. There is a gap, sometimes a chasm, between the intent of that ground-breaking legislation and the lived experience of people who need support. In the improvement world, there is a maxim which reads something like "every system is perfectly designed to get the results it gets". That is the basic challenge for us. We have inherited a system that gets unwarranted local variation, crisis intervention, a focus on inputs, a reliance on the market, and an undervalued workforce. If we want a different set of results, we need a different system."

The Review's analysis and recommendations were our North Star, shining a light on the state of social care in Scotland and laying out a path for the kind of National Care Service that we desperately need – one which delivers human rights, fairness, dignity, freedom and choices for disabled people. As it said, 'If not now, when?'

It has been said, this is Social Care in Scotland's 1948 moment, the date when our precious NHS was born, despite a backdrop of post-WWII austerity. We call on the Scottish Government, COSLA, Unions and all political parties, do not let this moment past. Let us all work together to make Social Care in Scotland as precious to the nation as the Scottish NHS.

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