The UK Deaf and Disabled People’s Monitoring Coalition is a secular network of user led Deaf and Disabled People’s Organisations across the United Kingdom.

This paper sets out the reasons why we are not able to support the Terminally Ill Adults (End of Life) bill following report stage.

Many of our concerns echo those voiced by the Royal College of Psychiatrists, Royal College of Physicians and Association of Palliative Medicine.

We do not believe the bill has received sufficient scrutiny for legislation that will so fundamentally impact the relationship between doctor and patient.

For the Abortion Act there was months of engagement prior to introducing the bill and for the Human Embryology and Fertilisation Act, there was the Warnock Commission.

For this bill there has been no direct consultation with marginalised groups and the speed and inaccessibility of the passage of the bill has been a barrier to engagement.

The equalities impact assessment is frighteningly lacking and there has been insufficient consideration of adverse equalities impacts in jurisdictions where it is legal.

For example, a lawsuit is being brought against California’s End of Life Option Act on the grounds that it puts disabled people at greater risk of being coerced into seeking assisted suicide.

At the same time, the opinions of professionals with the most relevant expertise have been largely ignored.

Below we set out our key concerns with the bill as it now stands, a list of the amendments we supported which would have improved safeguards but which were voted down and a list of amendments that have been held up as safeguards but which fail to ally our fears.

This paper concludes with our recommendations for MPs.

**KEY CONCERNS**

**No guaranteed access to palliative care.** The bill places a duty on the Secretary of State to guarantee access to assisted dying but not to palliative care. Where deaths in pain do occur, the person has not accessed specialist palliative care or accessed it too late or for too short a time. One in four people who need palliative care do not get it. Palliative care provision across the country is patchy and facing cuts with hospice care under-funded.

**No emphasis on suicide prevention.** This is one key reason why the Royal College of Psychiatrists are against this bill. Suicidal ideation and hopelessness are treatable including for people with terminal illness. There is no mandatory psychological assessment as part of the application process and people who both meet the eligibility criteria for the bill and have mental health diagnoses are not excluded.

**Inaccurate prognoses**. People who are terminally ill with six month prognoses may have many months and even years left to live. According to figures from the Department for Work and Pensions, one in five benefit claimants given less than 6 months to live are still alive three months later. This makes it less inevitable that people with terminal illness should want to end their lives.

**Inappropriate use of Mental Capacity Act as a safeguard.** The MCA was not designed for this purpose and has a presumption of capacity. It is possible to be assessed under the MCA as having capacity and yet having impaired judgement due to for example, depression, malnutrition or coercive control. Doctors will be trained in coercive control but psychiatrists and other professionals report how difficult this is to detect even with many years of experience.

**Insufficient provision for keeping people alive.** Changes to a person’s circumstances can change their wish to die. The place for a multi-disciplinary team assessment is at the very beginning of the process with the aim of identifying options to improve the person’s situation. Instead, the bill has a multi-disciplinary panel at the end of the process rubber-stamping applications for assisted dying with no requirement to meet the person. There is no requirement for a doctor to consult a specialist in the patient’s condition or for the patient to have a meeting with a palliative care specialist. Patients will be able to access assisted dying more quickly and easily than social care, mental health support or suitable housing.

**No requirement to include family members.** Evidence from jurisdictions where assisted dying is legal demonstrates how traumatic it can be for family members to lose their loved ones in this way, especially if they do not find out until after and especially if their loved one made their decision when experiencing impaired judgement. There is no right to appeal assisted dying decisions for family members.

**Safety concerns about assisted dying drugs.** Death by assisted suicide can be very unpleasant. The patient needs to swallow a large number of pills which the body may reject resulting in vomiting. The drugs used as the same as used for death row prisoners and have been linked to, for example, experiences of dry drowning. The bill impact assessment says the “safety and efficacy” of substances used for assisted dying is “currently difficult to assess”.

**Fear that assisted dying will replace access to services for terminally ill and disabled people wanting to live**. The impact assessment shows savings that will be made to both health and social care budgets through this bill. This has increased concerns that the choice to live will be removed for those of us who cost more in support. One care home group finance manager messaged colleagues about savings they could realise through “aggressive promotion” of assisted dying as an option for residents. The voting down of an amendment to limit advertising of the assisted dying service alongside costs in the impact assessment for an NHS education campaign is concerning.

**Insufficient attention to equalities impacts.** The equality impact assessment accompanying the bill was not published until after Committee stage and is unfit for purpose. It concentrates on equal access to the assisted dying service and omits many key risks in terms of adverse inequalities impacts, ignoring data on for example low levels of awareness and access to palliative care services by racialised minorities and those facing socio-economic disadvantage.

**Increasing non-assisted suicide rate.** There is no evidence that legalisation of assisted dying reduces non-assisted suicides. Research on the contrary shows a rise in the overall suicide rate even after accounting for those deaths by assisted dying. This is likely due to suicide contagion. This risk needs to be understood within the current UK context of escalating levels of mental distress and already increasing suicide rates. There has been no discussion of this or proposal of measures to mitigate this risk.

**Too great a reliance on Henry VIII powers.** A worrying amount in the bill delegates powers to Ministers to make secondary legislation without full Parliamentary scrutiny. This is even more concerning for a bill that will prompt the founding Act of the NHS to be opened up. Deaf and Disabled people are disproportionately reliant on the NHS and potentially at significant risk from this bill. This aspect of the bill is therefore of great concern to us.

**PROPOSED SAFEGUARDING CONCERNS THAT WERE VOTED DOWN**

**To close the anorexia loophole.** The bill gives eligibility to people where the physical condition that meets the criteria is either the result of a mental health condition or of Voluntary Stopping Eating and Drinking. This is a huge concern within the context of a mental health system unable to cope with demand where young women with severe and enduring eating disorders are routinely labelled as “hopeless cases” and transferred onto palliative instead of receiving the support they need to live. In other jurisdictions Voluntary Stopping Eating and Drinking (VSED) is used by people who don’t otherwise meet the eligibility criteria to gain access to assisted dying.

**To exclude from eligibility people with who are homeless and prisoners**. Disabled people are over-represented among both as are self-harm and suicidal ideation. Homelessness and conditions in prisons are growing problems. These amendments would have protected against people choosing assisted dying because of adverse external factors rather than the “clear, settled and informed wish to die” that is part of the eligibility criteria within the bill.

**Doctors to ensure that there are no remediable suicide risk factors before proceeding to the initial discussion about assisted dying and for psychosocial assessments to be conducted at the start of the process.** These amendmentswould have provided a safeguard against people with impaired judgement seeking assisted dying due to a mental health condition and/or suicidal ideation.

**To exclude from eligibility those seeking assisted dying for the benefit of others**. This could include financial concerns. This amendment would have been an important safeguard against coercion.

**To exclude from eligibility those seeking assisted dying because they feel like a burden.** This is particularly relevant within the context of inadequate social care support services so that family members and friends experience greater strain. Around one half of those seeking assisted dying in Oregon consistently cite being a burden as a primary reason compared to one third concerned about pain.

**To replace use of the Mental Capacity Act** to assess capacity to make a “clear, settled and informed wish to die” with a new ability test to assess ability to make a clear, settled and informed wish to die free from impaired judgement.

**For doctors not to be able to raise assisted dying with patients unless they mention it first.** This is a major concern for disabled people due to the prevalence of negative medical attitudes towards disabled people’s quality of life and the risk of medical coercion. This risk is evidenced by experiences during COVID when Do Not Resuscitate orders were unlawfully placed on the medical notes of disabled people without their consent as well as a weight of evidence concerning discrimination and medical negligence within the health system. An amendment not to permit doctors to raise assisted dying with children was voted down at Committee stage but accepted at Report stage.

**To prevent doctors from raising assisted dying as an option with people with learning disabilities and people who are autistic**. Instead, clause 20 provides access to independent advocates for people in this situation.

**Inclusion of a 28-day period between a terminal diagnosis and the start of the assisted suicide process.** This is important because fear and depression are common responses to terminal diagnoses. Practitioners in other jurisdictions told the Committee at oral evidence how giving patients the option of assisted dying when first diagnosed calms their fears and that many never end up taking the drugs because their fears over pain never materialise. As proven by the lived experience of our members, the same can be achieved by better support accompanying diagnosis, including, crucially, peer support.

**AMENDMENTS THAT FAIL TO ALLAY CONCERNS**

**Training for doctors in coercive control.**

According to professional opinions shared with the Committee, it is very difficult even for those with many years of experience to detect coercive control.

Much stronger safeguards would have been making psychological assessments mandatory as part of the application process and excluding from eligibility those feeling a burden and those acting for the benefit of others.

**Provision of independent advocates** **for “qualifying persons” including “those with learning disabilities, mental disorders, autism or other ‘substantial difficulties’ in understanding processes or information”.**

The focus of this clause is on access to information rather than protection from coercion. As a safeguard it is limited in that those willing to act as independent advocates will likely be in favour of assisted dying and may therefore have a bias towards ensuring access to the service that clouds their alertness from detecting coercion.

It is unclear from where the independent advocates for this role will be sourced.

**New multi-disciplinary panel** **including a psychiatrist and social worker.**

This will replace the role of the high court judge in rubber stamping approvals at the end of the application process and with no requirement to meet the person or involve their family.

The proper place for this panel is at the beginning of the process.

Multi-disciplinary team involvement is good practice when needing to identify holistic solutions for improving a person’s situation.

The role of the multi-disciplinary panel as prescribed by the bill represents a mis-use of MDT involvement. It will not enable the psychiatrist or social worker to utilise their expertise.

Professionals willing to be on these panels will likely be in favour of assisted dying and may therefore have a bias that limits their ability to detect coercion.

It is also unclear how these panels will be resourced given shortages within both psychiatry and social work.

**RECOMMENDATION**

We urge MPs to vote against this bill at third reading. A Private Members Bill is not the way to legislate on such a complex issue and one that puts large groups of the most disadvantaged members of society at significant risk for the benefit of a small minority. A Royal Commission where objective scrutiny can take place and that hears equally from all sides of the debate is needed. Due to insufficient transparency in jurisdictions where assisted dying is legal there is a dearth of evidence. Attempts to remedy this and to plug research gaps must also happen.