**Briefing on The Terminally Ill Adults (End of Life) Bill – Disabled People Against Cuts**

This briefing sets out key concerns about the above Bill, from the perspective of Deaf and Disabled people who are at significant risk from the Bill.

**Scrutiny of legislation:**

If Parliament supports assisted suicide in principle, then it must do so responsibly. That means a government-led bill which is informed by impact assessment and consultation with stakeholders and affected groups. **This private member’s bill does not meet that standard.**

All the information coming at MPs now is linked to one side or the other side. The first step in legislating for an issue of this significance must be comprehensive and reliable information that is robustly evidence-based through for example a royal commission. Among other things, there is a need for much better research into coercion in other jurisdictions where assisted suicide legal.

**Inadequate safeguards in the Bill:**

Even for those who support assisted suicide in principle, this Bill is unsafe. It does not contain adequate **protections to prevent unintended consequences** (such as including people with anorexia in scope) or either **explicit or implicit coercion** (such as by abusive family members/intimate partners, or through wider pressures on disabled people in particular).

Since the Committee stage **the Bill now has lesser safeguards than those it started with**. Expanding choice for some should not come at the expense of people who will be vulnerable to losing their lives because of this Bill. Introducing this Bill in a context in which many cannot access the care they need through the NHS creates a public safety risk, particularly for marginalised groups including many disabled people.

At Committee stage key amendments that were voted down included:

* Clauses aiming to deny eligibility to those seeking assisted suicide because they **feel they are a burden or have financial concerns, or are prisoners, or homeless, or on the grounds of anorexia**.
  + The Bill’s proponents appear either unwilling or unable to acknowledge that its current wording includes people with eating disorders within its scope. The fact is that while eating disorders are treatable illnesses, people with eating disorders may become extremely physically unwell if they are unable to access effective treatment or choose to refuse it due to the illness itself. The NHS struggles to provide timely, effective care for people with eating disorders, with rationing or delays in many areas. In England and Wales, the NHS has sought Court of Protection orders to withdraw treatment from patients with anorexia, who were described as “terminal”.
* Requiring a co-ordinating doctor to **refer the patient to an independent psychiatrist or qualified person**.
  + This amendment would have added a safeguard involving a qualified person to inform the view on whether the person has capacity, has a clear, settled and informed wish to end their life, and has not been coerced or pressured. So, illogically, the assessment process for assisted suicide will be less exacting than that for living organ donors.
* Preventing doctors from raising assisted suicide as an option with patients **even before the patient mentions it**, or from raising it with **children**

Meanwhile, the plan to involve the high court in decision-making on assisted suicide has been replaced by a **multi-disciplinary panel who won't even need to meet the patient**.

Moreover, the Bill as it stands does not adequately protect **victims of domestic abuse**:

* suicide following domestic abuse has overtaken homicide as the primary cause of domestic abuse-related deaths
* nearly 9 in 10 of unlawful assisted suicides in the UK currently are perpetrated by men against women – given the prevalence of domestic abuse these ‘mercy killings’ will very often be the outcome of abusive relationships
* disabled women are twice as likely to experience domestic abuse and also twice as likely to suffer assault and rape

Several other provisions and omissions give further cause for concern:

* There is no need for the patient to understand care options; **capacity will be assumed** unless proven otherwise; those with impairment of judgement due to mental illness still qualify.
* Training for doctors is not specified; there is **no explicit ban on encouraging** assisted suicide, undue influence or manipulation; lack of coercion must be found on ‘balance of probabilities’ not ‘beyond reasonable doubt’.
* There is **no requirement to inform family**; no avenue for appeal if they believe a mistake has been made.
* Doctors **don’t need ‘reasonable certainty’** that the applicant has six months to live, just the balance of probabilities.
* The Bill does not provide for a guaranteed palliative care consultation; patients must be told what care is ‘appropriate’ but not whether it is available; there is **no need to consult a specialist in the patient’s condition**.
* Hospices/care homes have **no right to opt out** and no guarantee they won’t lose public funding for not offering assisted suicide.

Note that only 18% of amendments accepted were from MPs who opposed the bill at second reading.

**Right to life:**

The Human Rights Act 1998 Article 2 (read with Article 14) places obligations on Government to protect the right to life, without discrimination. The right to life does not include a right to die (e.g. Pretty v United Kingdom 2002).

Article 10 of the UN Convention on the Rights of Persons with Disabilities provides that states shall: “reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others”.

As a Private Members’ Bill, the requirement under the Human Rights Act 1998 for a minister to declare its **compatibility with human rights** does not apply; moreover, the Bill was not accompanied by an as yet unnpublished **equality impact assessment**. The promoters of the Bill have not given adequate consideration to the human rights and equality implications of the Bill’s provisions.

**Disabled people’s stake in the outcome of the Bill process:**

Deaf and Disabled people, including people living with mental distress, are:

* nearly one in four of the population
* more likely to die early and from preventable illnesses
* subject to unequal access to healthcare.

If Parliament passes the Bill and there is then a subsequent ECtHR ruling that restricting the legislation to terminally ill adults is discriminatory, it would be the responsibility of a Minister to take remedial action to remove the **incompatibility with the European Convention on Human Rights**. This would not involve scrutiny by Parliament. This could mean an expansion of assisted suicide to cover disability and mental health conditions.

**Involving disabled people in the process:**

Article 29 of the UN Convention on the Rights of Persons with Disabilities provides that states shall: “ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others… [and] promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs”.

However, **disabled people and our organisations have been actively excluded** from most of the proceedings of the Bill Committee; the process has also ignored duties under the Equality Act 2010 with information not being provided in an accessible manner.

**Conclusion**

Legalising assisted suicide will result in people choosing to end their lives early not because they want to but because of **inadequate support to continue to live**, in the context of a struggling NHS. In Oregon only one third of those granted assisted suicide have applied because of pain. Lack of support including psychological support for those who are terminally ill play a much bigger role.

In the UK we need to **fix the foundations first** – our health, social care, mental health and palliative care systems and also our social security system, which already drives many disabled people into **destitution and desperation**.