Written Evidence Submission – Assisted Dying (Terminally Ill) Adults bill

**Introduction**

We are a secular, human rights network of organisations run and controlled by Deaf and Disabled people (DDPOs) from across the UK. We monitor and campaign for implementation of the UN Convention on the Rights of Disabled People, promoting the interests of 16.1 million Disabled people. This includes those who are terminally ill and who live with progressive, life-threatening conditions.

We are extremely concerned that the bill has insufficient safeguards to prevent abuse, discrimination and adverse equalities impacts for Deaf and Disabled people. Without significant strengthening the bill in a number of areas, we consider it too unsafe to progress.

**List of major concerns and recommendations**

Major concern: the eligibility criteria are insufficient to rule out AD being sought for reasons of disability rather than terminal illness [clause X]. Recommendation: amend eligibility criteria from “can be reasonably expected to die” to “cannot reasonably be expected to live even with all available treatment.”

Major concern: doctors can raise AD as an option to patients [clause X]. This is a particular worry for disabled people on account of evidence of medical coercion and negative judgements about the quality of our lives made by medical professionals resulting in deaths by neglect and/or denial of life-saving treatment. Recommendation: patients must raise AD themselves before doctors can discuss it with them.

Major concern: whether doctors will be able to spot coercion and in particular signs of coercive control [clause X]. This is a particular concern for us since disabled people are three times more likely to experience domestic abuse than non-disabled people. Inadequate social care and mental health support provision increasingly leads to Deaf and Disabled people feeling like a burden on our family and friends. Recommendation: mandatory training for doctors eligible to carry out AD assessments in coercion, coercive control and disability equality; amend for all patients requesting AD to first go through assessment carried out by a qualified psychiatrist.

Major concern: whether doctors will be able to spot where patients are experiencing depression that could be remedied through psychological support and/or alternative support provision [clause X]. Recommendation: all patients requesting AD to first be referred for an assessment carried out by a qualified psychiatrist.

Major concern: unsuitability of Mental Capacity Act as test for whether a patient can make a settled and informed wish to end their life [clause X]. Recommendation: develop a new test for the specific purposes of this bill to be defined in statutory guidance put forward by the Secretary of State through affirmative procedure; amend for all patients requesting AS to first go through assessment carried out by a qualified psychiatrist.

Major concern: available support [clause X]. Recommendation: amend to

Major concern: reporting requirements are insufficient to allow for adequate transparency and scrutiny; Recommendation: amend to require annual reporting of Assisted Suicides to provide a full breakdown of illness/condition as well as comorbidities; full equalities breakdown and breakdown of the main reasons why AS was sought.

**Other concerns and recommendations**

Concern: six month prognoses are highly inaccurate [clause X]. Amend: to reduce eligibility down from 6 months to 6 weeks.

Concern: no opt out for doctors [clause X]. Recommendation: amend to allow doctors to opt out of participation in any aspect of AS.

Concern: the first doctor refers the patient on to the second doctor [clause X]. Recommendation: second doctor must be fully independent of the second.

Concern: patients must be able to fully understand all information they are given. Despite Equality Act and NHS Communication standards medical appointments still happen without eg BSLi. Recommendation: make it an offence for appointments to go ahead without fully qualified BSL interpreter, or independent advocate.

Concern: coroner inquest

Concern: family appeal

**About us**

The UK Coalition was set up in 2017 following joint working between UK DDPOs to shadow report to the United Nations on Deaf and Disabled people’s experiences of implementation of the United Nations Convention on the Rights of Disabled people (UNCRDP). Since then, we have submitted joint annual shadow reports (except during Covid) and worked together on joint written and oral evidence for a follow up to their special inquiry carried out by the Committee in August 2023 and March 2024.

We also work together to lobby and campaign on shared priority areas and to progress enshrinement of the UNCRDP.

Our organisations follow the social and human rights models of disability and the cultural model of Deafness.

Disabled people include people with physical/mobility impairments, sensory impairments, learning difficulties/disabilities, mental distress, long-term health conditions, energy limiting chronic illness, autistic people and people who are neurodivergent.

Disabled people experience multiple layers of disadvantage. We are over-represented among those who are living in poverty, in low paid and insecure work, homeless, least likely to have educational qualifications and who have caring responsibilities.

**Why this bill affects disabled people**

We die too!

Terminally ill disabled patients situations worse housing, lack of social care,

Negative medical judgments eg lung transplant, covid, dnacprs

Blurred boundaries – anorexia; progressive conditions