

We, the undersigned, urge parliament to consider the urgent concerns of our organisations and members in regard to the Terminally Ill Adults (End of Life) Bill (Assisted Dying Bill), and the impact of this legislation on individuals with Down syndrome and learning disabilities, their families and related professionals.

Our key concerns include:

1. **Overlooked Disability Perspectives:** The overwhelming majority of UK disability organisations oppose the bill, citing risks to their communities. Their expert insights and experience are crucial and should not be ignored.
2. **Rushed Consultation Process:** The bill's accelerated timeline has not adhered to the recommended 12-16 week public consultation period, limiting comprehensive input and risking oversight of diverse societal values.
3. **Limited Professional and Affected Population Engagement:** Insufficient time for thorough analysis by healthcare professionals and inadequate engagement with affected and marginalised groups directly at risk from this legislation. [Elderly and disabled groups blocked from giving assisted dying evidence](#)
4. **Lack of Accessible Consultation Materials:** Failure to provide Easy-Read materials and other necessary adaptations in line with government process has excluded individuals with learning disabilities from participating equitably in the consultation on legislation which impacts them.
5. **Vulnerability to Coercion:** Individuals with intellectual disabilities can be highly susceptible to coercion and may struggle to fully understand and consent to end-of-life decisions, with and without appropriate adjustments being made.
6. **Communication barriers:** subjective interpretations and lack of specialist training may lead to misunderstandings of the true wishes of individuals with disabilities.
7. **Fluctuating Mental Capacity and Subjective Assessments:** Accessing mental capacity in individuals with learning disabilities is complex and presents significant challenges. NHS England highlights capacity is 'time and decision-specific' and fluctuates. The **Mental Health Act** recommendations can be conflicting, and open to interpretation and abuse, providing no failproof safeguard for the vulnerable.
8. **Increased Dependency:** As individuals with learning disabilities now often outlive their parents, their reliance on healthcare professionals and state representatives for decision-making increases. However, these 'safeguards' frequently fail individuals, as seen during the pandemic with illegal 'Do Not Resuscitate' notices (Govt inquiry) and 42% of deaths among people with learning disability being avoidable (LeDeR Report).
9. **Discriminatory Legislative Focus:** The bill prioritises end-of-life options for a relatively small number of terminally ill people over the many thousands the legislation puts at risk, without first exploring and enhancing pain management and palliative care solutions.
10. **Unreliable Scope Limitations:** Safeguard assurances simply cannot ensure that the scope of the law remains narrow indefinitely. In all countries with similar laws, the criteria for assisted dying broadened rapidly. Canada expanded eligibility from 'terminal illnesses' in 2016 to include non-life-threatening conditions by 2021. 35% of those who died by medical assistance reporting being motivated by being a "perceived burden on family, friends or caregivers". In the Netherlands, the scope also rapidly widened, leading to the euthanasia of 40 individuals with autism or learning disabilities between 2020-2021.
11. **Value of Life and Overemphasis on Disability:** There is a potential for assisted dying laws to devalue lives based on disability, combined with common misconceptions about the quality of life for those with disabilities.

Our concerns highlight the need for a more cautious, inclusive, and comprehensive examination of the proposed legislation to ensure it does not inadvertently harm the most vulnerable in society as already evidenced in other countries. We strongly urge Parliament to duly consider its safeguarding duties and

take these points into account during the bill's deliberation to ensure a balanced, informed and robust legislative outcome which upholds and safeguards **everyone's** human rights.

- All Wales People First
- Andover 21
- Bolton Smiley Faces
- Bromley Down Syndrome Support Group
- Buckinghamshire Disability Service (BUDs)
- Cambridgeshire Babies and children with Down Syndrome
- Cambridge Down Syndrome Support Group
- Cheshire Down Syndrome Group
- Cornwall Accessible Activities Program UK
- Cornwall Local Policy Advisory Group
- Cornwall Down Syndrome Group
- Daisy's 21 Wishes DS Support, Herts
- Diff-Ability Scotland, NE & NW England
- Disability Cornwall and Isles of Scilly
- Don't Screen Us Out, UK
- Down's and Special Friends Charity
- Down Right Brilliant- Newny and Mourne Down's Syndrome Support Group
- Down Right Worthy, Cumbria
- Down's Syndrome Scotland
- Down's South, London
- Down's Syndrome Oxford
- Down's Syndrome Research Foundation, UK
- Down Syndrome UK
- East Lancashire DS Support Group
- Fionnathan Productions
- North Lancashire DS Support Group
- Not Dead Yet, UK
- Get on Down's, SW and Greater London
- Glasgow Disability Alliance
- Just the Way You Are MK
- National Down Syndrome Advisory Group
- National Down Syndrome Policy Group
- Panda's Tree Black Down Syndrome UK
- Parent Carers Cornwall
- Parent Carer Forum Cheshire West
- Playwise Learning CIC, Sutton
- Portsmouth Down Syndrome Association, Hants and surrounding counties
- Pershore & Evesham DS Support Group (PEDDS)
- Positive About Down Syndrome
- Project 21, Cambridge, Essex, Suffolk
- Reverse Rett, UK
- Rochdale All Stars
- Shades of Different CIO, Dorset+
- Sheffield Down Syndrome Group
- Shine 21, Dorset
- Shropshire Down Syndrome Support Group
- Sparkles: DS Support, Bucks
- Stage 21, UK
- Stoke and Staffordshire DS Support Group
- Sundowns DS Family Support
- Sunshine and Smiles Leeds
- 21 and Co, South West London and Surrey
- T:21 Dragons, East Sussex
- T21 Brighton and Hove
- Talk More Cornwall CIC
- The Lejeune Clinic
- The OWL Therapy Centre, UK
- Ups n Downs, Northamptonshire
- The Ups of Downs, Warwickshire and surrounding counties
- Upwards with Downs, Essex and Herts
- Wouldn't Change A Thing, UK