**Scorn not his simplicity**

*See the child
With the golden hair
Yet eyes that show the emptiness inside.
Do we know,
Can we understand, just how he feels -
Or have we really tried?*

*See him now
As he stands alone
And watches children play at children’s games.
Simple child:
He looks almost like the others
Yet they know he's not the same.*

Why should parents feel forced to plead for the life of a child, be compelled to beg that others see their son or daughter as a uniquely beautiful human being? When the renowned musician and songwriter Phil Coulter wrote his song, “Scorn not his simplicity”, he tried to express, in words and music, his personal experiences following the birth of his first child, a boy with Down’s syndrome. The heartbreaking agony of the lyrics extends far beyond their quality as a musical score or as a title on a record label. Coulter speaks of his wife, describing,

*How she cried tears of happiness
The day the doctor told her it's a boy.
Now she cries tears of helplessness
And thinks of all the things he can't enjoy.*

Comic actress Sally Phillips explained in an interview with *The Telegraph* that “You go home to deal with the ‘bad news’ and you have friends and family who come round and get drunk and talk about the ‘bad news’ and it’s all like something dreadful has happened. And something important has happened and you’re going to have to let go of some of the dreams you had, but it’s really not as bad as everyone makes out.”

Phil Coulter revealed his family’s experiences in song. Sally Phillips wrote and co- presented her first-ever television documentary, A World Without Down’s Syndrome? in which she features her son Olly. She meets other parents, each with with their own story and concludes, “People aren’t fascinated by the things people with Down’s syndrome can do better, which are: relate to people, be funny, be comfortable in their own bodies.” Sally’s hour-long documentary can be summarised in the words penned by Phil Coulter in the early 70s:

*Scorn not his simplicity
But rather try to love him all the more.
Scorn not his simplicity.*

My busy schedule meant that I watched A World Without Down’s Syndrome? in two sessions rather than in one. Coincidentally or providentially the bus journey which interrupted my viewing included two separate encounters with young men who have Down’s. One casually leaned against a bus stop, using his mobile phone. The other travelled independently as a fellow commuter on “my” bus. Only the syndrome’s tell-tale physical characteristics distinguished them from the seething mass of rush hour humanity.

Why should a medical diagnosis cause some parents to end the life of their unborn child and others to celebrate the difference? Why is Down’s syndrome so emotive? When an unborn life is terminated because of disability, how often is it because parents fear they might not cope with their baby’s unique needs, imagining consequences which, in reality, they might never have had to face? How often do health professionals pressurise parents into an action with lifelong consequences? One woman recently commented that, because she had not wanted her baby to experience pain, he did not receive the chance of life.

As a student midwife, I once welcomed a woman in her mid-forties into the clinic and heard her almost explosive joy on being pregnant after twenty years of trying for a baby. “I want this baby whatever happens”, she declared. A junior doctor entered the room to conduct the customary ante-natal examination. Instead of congratulating the woman, he spoke at length about her “advanced age”, stressing that she consider amniocentesis and possible termination should there be any indications of disability. Within the space of a few minutes, he changed a woman’s happiness into abject misery and fear.

There are deeply heart-breaking situations. One woman for whom I cared in Zambia had had eleven miscarriages. On delivering a baby with Down’s, she secretly walked out of the hospital, abandoning the infant – and her husband divorced her, not because of leaving the baby but because he felt that the little one’s condition reflected negatively on his manhood!

Lord Kevin Shinkwin’s recent Private Member’s Bill in the House of Lords could remove two clauses from the UK’s 1967 Abortion Act and prevent the targeted abortion of babies with an ante-natally diagnosed disability. He himself suffers from the painful and rare brittle bone disease and so knows from personal experience the consequences of living with serious ill health.

Lord Shinkwin argued that, “discrimination on the grounds of disability after birth is outlawed. Yet today legal and lethal discrimination on the grounds of disability is allowed up to birth by law. It is illegal for an unborn human being to have their life ended by abortion beyond 24 weeks, but if they have a disability their life can be ended right up to birth by law. Where is the consistency, the justice or the equality in that?”

In response, Lord Alton of Liverpool remarked, “We live in a country where around ninety percent of all Down’s syndrome babies are routinely aborted.” He pointed out a glaring inconsistency, that if Lord Shinkwin’s Bill “had set out to facilitate the assisted suicide of disabled people, it would have been on every national news bulletin. But because it seeks to end the taking of the life of a viable disabled baby, it is being treated very differently.”

Alton highlighted the worrying fact that “unwillingness to treat ethical issues with equal respect and impartiality is a disturbing sign of the times - but not as disturbing as the issues of equality, discrimination and the very right to life itself.” He added that, “our legislation currently affords unborn disabled babies significantly less protection than that which is afforded those who are able-bodied. Paradoxically, we will campaign and raise our voices for wheelchair ramps to be placed on public buildings but fail to uphold the innate right to life itself of the disabled person who uses that wheelchair.”

Frighteningly, and illustrated by the Zambian woman, divorced for giving birth to a baby with Down’s, there is a suggestion of a two-tier scale of human worth. As Lord Alton declared, “Although the able-bodied may be aborted up to 24 weeks, those who are disabled may be aborted up to birth. This inevitably implies that these unborn disabled babies are… significantly less valuable than those who are able-bodied. What message does this convey about the human dignity and the value - or, rather, the lack of value - of disability in society generally? As the law stands, it is a legal arrangement that invites and encourages discrimination.”

Perhaps Lords Shinkwin, Alton and Phil Coulter could have happily used the House of Lords debate to sing together and to proclaim to the world, on behalf of all people with disabilities, both born and unborn:

*Only he knows how to face the future*

*Hopefully. Surrounded by despair*

*He won't ask for your pity or your sympathy*

*But surely you should care.*

*Scorn not his simplicity*

*But rather try to love him all the more.*

*Scorn not his simplicity.*