

Janet Goodall argues that disabled children bring secret and special gifts

David and Maryann Lovatt and their Down's syndrome four-year-old daughter Louise, from Springfield, Chelmsford, Essex, in London, where TV weather girl Sian Lloyd launched a £21 million appeal to raise funds to help families cope with mentally disabled relatives.

The pearl effect

KEY POINTS

In a culture that views success and failure in materialistic terms, many perceive disabled children as an extra burden. But paradoxically, divorce rates and unhappiness are no more common in the families of disabled children than in those with healthy children. Like the grit in the oyster that causes a pearl to form, caring for a child with special needs often strengthens relational bonds and encourages spiritual growth. As the agony of Gethsemane led to resurrection life, so the reciprocal love between the disabled child and his parents and the care shown by professionals, families and churches can act as a catalyst for maturity and stability.

Twenty years after a paediatrician broke the news that her disabled baby would not survive, a mother spoke about how she had been introduced to the hospital chaplain. 'We'd not been religious before but my husband and I both became Christians and so did thirteen members of our family. Now I arrange Christian teaching for over 100 women in the city, and it all stems from the short life of our baby girl.' Like grit in the oyster, something uniquely painful had become productive.

This story encourages a more perceptive approach to disability, all the more urgent in a culture that measures success and failure in materialistic terms. Expectations change along with attitudes. Years ago, badly disabled babies were kept in hospital and parental visits discouraged. Sharing a painful diagnosis with families could be deliberately delayed. I know of two parents who waited months to be told bluntly that their child was a 'mongol'; asked to use a different expression, the doctor heartlessly replied, 'You can say "idiot" if you'd rather'. Today, although one in 50 newborn babies have a significant defect, the best units will keep parents sensitively informed and encourage early interaction with their infants.¹ Even so, parents can have a sense of shocked inadequacy, their baby sometimes being viewed as substandard. There is an occasional suspicion that health funds will go to more rewarding conditions.²

Professional dichotomy

For some sick newborn babies, battle is waged with all possible technological armory. For others there can be a temptation to hasten the end. Such fighting and fleeing are forms of denial, often shared for a time by both professionals and parents before better balance is achieved. For some infants, palliative care would be appropriate but prejudice can overlook that option.³ Should the 'fight' become litigious or the 'flight' involve rejecting the baby, emotional progress is often thwarted. Without insight, staff-parent-child relationships can be fatally damaged and abscesses form instead of pearls.

Philosophical debate

Bioethicist Peter Singer has asserted that a normal week-old baby is a non-person and so its infanticide need not cause inquietude. His use of 'it' betrays an impersonal view of a little boy or girl who, he says, is inferior in rationality and value to many animals.⁴ Denial itself is emotional, not rational, yet must under-gird this philosophy. That he would yield to parents who prefer their babies to live suggests that loving commitment can defy 'reason'. Love values what others demean.

Philosophers (and others) should know a normal infant can show preference for their mother's smell, voice and face within days of birth. Breastfeeding strengthens face-to-face attentiveness, an

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anatomical impossibility for mammals but not for disabled human babies.⁵ Within weeks, interactive infants can indicate recognition of their parents, implying recall if not yet rationality.

Studies that may surprise

In a retrospective study of infants with inoperable spina bifida, parents encouraged to care for their child at home reported stronger family ties than those confined to hospital based care.⁶ Involved parents appeared significantly more serene and saw themselves as wiser and better people. In these poignantly painful circumstances, agape love was given a growth spurt. Still, is this enough to keep parents of disabled children united? The marital strain they face could be said to justify early infanticide. Yet healthy children also bring problems and many childless marriages break up. A study comparing healthy school children with their mentally or physically disabled peers showed no difference in parental divorce rates, unless social deprivation had contributed both to developmental delay and family stress.⁷

Society often thinks of disabled lives as being unhappy. A study compared the mental states of both healthy and variously disabled school children. It was the older, healthy children who most significantly expressed frustration, worry or alienation. The disabled group favoured activities shared with companions; this tallies with the closer relational bonds described by the interactive parents of spina bifida babies. Whilst our culture promotes autonomy, it seems that the interdependence of these families acts as their cement.⁸

Research territory still to be explored

Old assumptions yield new research. Abortion, often advised for anxieties such as fetal anomaly, is now shown to risk unseen as well as unwelcome legacies.^{9,10,11} As yet, few studies of disability look into less readily measurable criteria. Like our opening story, evidence for a harvest of pearls tends to be anecdotal or biographical.^{12,13,14} Closer scrutiny is needed, but there are already clues to pursue.

Despite times of exasperation and bewilderment, the mother of a teenager with cerebral palsy wrote, 'The world of the handicapped is one of the most

warm and loving sections of our community. We also realise that it is one of the most neglected and misunderstood but the genuine warmth and affection given by and to handicapped people is most rewarding'. Surely our fractured society needs such an asset.

The child with Down's syndrome, so dismissively labeled 'idiot', had three older sisters who all eventually entered caring professions. It would be interesting to explore a possible correlation between caring careers and a background of illness or disability within the carer's own family. Those with supposedly limited abilities may prove to be donors, not debtors, to our social services.

What about disabled people themselves? Do they wish they had never been born? Attempted suicide is common amongst healthy adolescents. Comparative figures would be interesting. Instead, many disabled people lead uniquely inspiring lives, worthy of wider recognition; for example, I know of a Christian woman, paraplegic from spina bifida and in constant pain, who maintains and visits a home for disabled children in India.

The image of God

Why, then, do some disabled families find pearls whilst others form abscesses? Personality must play a part but Paul Tournier believed that a sufferer's reaction to suffering depends more on support received than on hereditary disposition. 'Deprivations without the aid of love spell catastrophe...the decisive factor in making deprivation bear fruit is love.'¹⁵ This is both the reciprocal love so often seen between a disabled child and his/her parents and care and support by professionals, families and church fellowships. Christians will seek to channel the love of God when breaking bad news or in looking for ongoing help for those so heavily burdened. Our God is a three-in-one deity, suggesting that part of his image in us should be our inter-relatedness. Keeping step with his Spirit will channel his costly love into many a bad situation, often helping the sufferers to commit themselves and their outcome into his hands. Then, as with the passion of our Lord, the agony of Gethsemane can lead to resurrection life. His love in action will soothe pain and form pearls.

Atheists and agnostics often cite the sufferings of disabled children as grounds for unbelief. Materialists may deny them adequate funding or even life itself. There is an urgent need to present credible evidence that attention to the personal needs of disabled people is not only good and proper but can also enhance the hidden contributions they make to our communal welfare. It is easier to count the acknowledged cost of their special needs than to value the secret and special gifts that they so often bring.

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