

Capacity to enjoy longer life

The annotation by Bittles and Glasson¹ confirms trends noted worldwide of improved life expectancy not only for people with Down syndrome but also for those with other disabilities, including cerebral palsy. Mortality rates in Down syndrome are now improving at a rate greater than those of the general population. The move from institutional to community care in developed countries has been met with an improvement in nutrition, lower infection risk and, with life holding more outside the institutional walls, overwhelmingly, an improvement in spirit.

Arithmetic means are sensitive to outliers and improved mortality rates in early infancy have contributed significantly to the noted trend. The indifference, and at times negative attitudes noted by Silverman² in the 1980s, of doctors towards Down syndrome, has largely been replaced by a far more positive approach. Survival following cardiac surgery is now as good as that seen in all children. This has an important influence on mortality rates, as up to half of children with Down syndrome have congenital heart disease. A service review has emphasized the need to support and communicate well with families at a time when they are faced not only with disability but with the prospect of major surgery; the review also called for doctors to present a balanced view of treatment options.³ A major point from the report and subsequent commentary is that life-prolonging treatment is in the interest of people with Down syndrome and that most people with Down syndrome do have a good quality of life, certainly as judged by them. It follows that equality of access to treatment options should be maintained.⁴ Improved treatment of leukaemia, which affects 1 per cent of young people with Down syndrome, has also increased life expectancy. Chessels⁵ has highlighted how, over the past decade, improved knowledge of how to use chemotherapeutic agents and antimicrobials has enhanced survival. We know that over-expression of cystathionine synthetase is associated with very low levels of atheroma and that solid tumours and multiple sclerosis are seen only very rarely in Down syndrome. One biological disadvantage of Down syndrome is the overactivity of superoxide dismutase, leading to increased intracellular oxidative activity and a process akin to accelerated aging. Great interest is, therefore, currently centred on the possible long-term benefit of antioxidants with the possibility of delaying the onset of Alzheimer's disease, which affects up to 50% of adults with Down syndrome.

Are these scientific advances matched by improvement in medical practice? GK Chesterton said 'I do not know what I think about a thing until I hear what I say'. Increasingly, doctors are talking of 'giving' the news following the birth of a new baby with Down syndrome – which as Bittles and Glasson point out is an increasing occurrence – rather than 'breaking' the news. The implication is that the arrival of a child with a disability is not necessarily a bad thing, there are positive aspects too. Families adjust following the early disappointment and live to laugh again. A doctor's positive attitude, attained through

self-knowledge and addressing existing attitudes and fears, contributes to a positive health-care delivery system.

Ideally, this improvement in approach by medicine should be matched by positive changes in society at large. In the educational world, since the 1980s, legislation has emphasized a preference for mainstream education for children with special needs and extended disability rights to the education and further education systems. There are now young adults just leaving school who have had the benefit of this new approach. There is a new peer group generation who support and look out for young people with disabilities. Young people who have benefited from an education alongside a child with a learning disability think of how they might help them to achieve, and their starting position is to include rather than exclude. This is likely to impact on employment decisions in the future.

At present in the UK, employment opportunity is meagre but organizations such as Connexions are seeking opportunities (www.connexions.gov.uk). Legislation has defined learning disability for the first time and set down a requirement for an annual report to parliament on the 'Development of health and social services for persons with learning disability'. At the time of writing, further draft legislation is looking to promote increased positive attitudes to disability. It will emphasize human rights and get away from the age-old confusion between mental illness and mental disability.

The UK is one of the countries taking a lead in these developments, though sadly in many others little progress is being made. Where there is change, it is encouraging to note that improved life expectancy is not only reflecting positive changes in health-care delivery but also society's growing capacity, rather than incapacity, to accommodate, not a burden, but an enriching group of young people.

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