

Resources, Down's syndrome, and cardiac surgery

Do we really want "equality of access"?

One of the "most taxing issues" addressed by last month's report of the Independent Inquiries into Paediatric Cardiac Services at the Royal Brompton Hospital and Harefield Hospital¹ was the allegation that children with Down's syndrome were discriminated against at the Royal Brompton Hospital. It was alleged (but not proved) that children were inappropriately "steered away" from surgery for heart defects because they had Down's syndrome. The report recommends that: "The Trust's policies confirm clearly that people with a disability are entitled to, and will be accorded ... the same rights of access to services as those without a disability; and that consultants should take the lead in implementing policies and influencing attitudes regarding equality of access." Similarly, a guiding principle in the report's model guidance to avoid discrimination is that: "Access to services, and priority for treatment, should be determined only on the basis of clinical need." The principle of equality of access is thus equal treatment for equal need.

Equality of access is uncontroversial when there are resources to treat everyone. It would then be unfair discrimination to deny a child lifesaving surgery because she had a disability—unless one believed her disability was so severe that it was not in her interests to continue to live. Until a few years ago some doctors did believe that about Down's syndrome.³ Such a view is now roundly rejected. One of the report's major points is that prolonging treatment is in the interests of a person with Down's syndrome.

Equality of access is problematic, however, when resources are scarce. The report admits there were serious shortcomings in resources for cardiac surgery in the 1980s and early 1990s, though it is difficult to judge how relevant these were to treatment decisions. However, resource considerations are critical when evaluating any principle of equality of access.

Consider the current situation over heart transplantation in children (not performed at the Brompton). Some children with Down's syndrome need a heart transplant. Should they be placed on the waiting list? A Channel 4 edition of *Inside Out* reported one case of a child who was denied heart-lung transplantation because of her Down's syndrome.⁴ Her mother believed the medical argument was: "There are so few organs they're not going to waste one on my child."

In Australia about a third of children waiting for heart transplants die before transplantation because of the scarcity of hearts. With a severe shortage of hearts, transplanting a child with Down's syndrome implies

that a child without Down's syndrome will die who would otherwise have received a transplant.

Should quality of life be a relevant factor in deciding how to allocate scarce resources? The Brompton report was critical of reference to quality of life evaluations and "value judgements—for example related to factors such as limited lifespan, inability to get the most out of life, or not being a burden upon others or upon society." Equality of access urges us to ignore such considerations. So does the law. The European Convention on Human Rights 1950 states: "Everyone's right to life shall be protected by law ... No one shall be deprived of his right to life intentionally" and "The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour ... or other status." Denying children with Down's syndrome access to transplants is therefore probably unlawful discrimination.

Yet we *do* appeal to quality of life in deciding how much benefit people derive from scarce resources. For example, people with brain injury or dementia resulting in a severely impaired cognitive state (such that they cannot interact socially with other people) may be denied transplantation, not because it is against their interests, but because the scarce organs would do more good if directed to a person without such impairments. Quality of life *is* taken into account when allocating organs, as when hearts are matched to recipients of a similar size to provide the best functional result.

If we appeal to equality of access and fail to consider the magnitude of the benefit a person expects to derive from treatment, absurd consequences follow. Equality of access requires that we ignore not just quality of life but also its length. Imagine George is 1 year old and has a metabolic abnormality. He will die in one year, but without a transplant he will die in the next few weeks. John is also 1 year old and has cardiomyopathy and could expect up to 20 years of life if he receives a heart transplant. According to equality of access, both need a heart transplant to live, so both should have an equal chance. This seems absurd. We should give priority to John.

The idea of equality of access is that each of us has a life of equal value, and arbitrary factors like disability should not be considered in determining eligibility for treatment. John Harris claims that each rational person wants *for himself or herself* at least three things from health care: (a) the maximum possible life expectancy; (b) the best quality of life; and (c) the best opportunity

or chance of getting both.⁵ Treating people as equals involves giving equal weight to each person's own claim. As Harris recognised, a principle of equality cannot be selectively invoked only by those with disability but also applies to those who happen to have poor prognoses or diseases that are expensive to treat.⁶

Equality of access thus requires that we ignore the probability of survival. This is inconsistent with accepted practice. Every day older women in Britain are denied in vitro fertilisation because they have a lower chance of a successful outcome. We do not follow the principle that "anything goes" irrespective of likelihood of success. In 1995 Jaymee Bowen (Child B) was denied a second bone marrow transplant for leukaemia because it would cost £75 000 and there was little chance of success. Her father took Cambridge Health Authority to court. Sir Thomas Bingham, Master of the Rolls, appealed to a principle of maximising benefit when he rejected the father's appeal: "Difficult and agonizing judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients."⁷ Indeed, the General Medical Council has stated that "the clinical team in determining priorities and the utilisation of the resources made available to them by the NHS is entitled to take into account the likely success of the treatment proposed."⁸

Under conditions of sufficient resources, equality of access is ethically mandated. However, under conditions of insufficient resources to treat everyone (and these will always be with us), unthinking application of the principle of equality means fewer people will live, and those who do live will live shorter and worse quality lives. It also rejects a cost effectiveness approach to maximising benefits to different but mutually exclusive populations of patients.

We should face reality: quality and length of life and probability of benefit (and cost of treatment) are relevant in determining who should receive treatment. Severe disability in some circumstances should disqualify a person from access to scarce resources. With the current shortage of donor hearts, it would be wrong to transplant a barely conscious child with severe intellectual disability or a child with congenital myotonia dystrophica dependent on a ventilator.

It is probably unlawful to place lower priority on children with Down's syndrome and other disabilities

who need heart transplants. But is it unethical? Doctors cannot and should not be involved in fine grained evaluations of the worthiness of different lives,⁹ and a tolerant and affluent society would strive to provide equality of access to everyone for as many interventions as possible. Whether disability such as Down's syndrome should be considered relevant in allocating a scarce resource turns on how much the disability associated with it detracts from a good life.¹⁰

Down's syndrome is associated with intellectual disability, infertility, reduced opportunities for independent living and employment, shorter life, and early onset Alzheimer's disease. These all make those lives worse. But considerable variation exists in the quality of life of people with disability, particularly those with Down's syndrome. A person with intellectual disability can have a happy and worthwhile life. This is why it is essential to judge every case for heart transplantation on its merits, assessing all the factors, but including the likelihood of a good outcome in any particular case.

But there are better alternatives. We could increase the amount we spend on health. In the case of transplantation we could change our selfish and unreflective attitudes to organ donation by moving to an opt out system for organ donation. One terrible constraint that forces us to decide between people would then be removed.

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- 2 Kmietowicz Z. Down's children received "less favourable" hospital treatment. *BMJ* 2001;322:815.
- 3 Molenaar JC. The legal investigation of a decision not to operate on an infant with Down's syndrome and duodenal atresia. *Bioethics* 1992;6:35-40.
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- 7 *R v Cambridge Health Authority, ex p B* [1995] 2 All ER 129, 133 (CA).
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Synchronous chemoradiation for squamous carcinomas

This has become the new gold standard—whatever the primary site

For many decades the primary treatment for common cancers has mostly been radical surgical resection (for example, for cancers of the large bowel, lung (non-small cell), kidney) or radical radiotherapy for inoperable cases or when tissue preservation is desirable and the cancer sufficiently radio-sensitive (for example, cancers of the head and neck, notably larynx). Surgery and radical radiotherapy are

sometimes competitors, but in other cancers (such as breast cancer) limited surgical intervention and radiotherapy used conjointly can offer the best compromise between the twin requirements of excellent local control with tissue preservation and near perfect cosmesis. Over the past few years a quiet revolution has been taking place, dramatically altering the treatment options in a surprisingly large proportion

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