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People with intellectual disabilities

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mortality as the outcome measure. These limitations aside, the paper highlights that newly appointed surgeons are able to deliver extraordinarily good results, especially for low risk patients.

In another paper in this issue Keogh et al explain the background to public reporting of cardiac surgical outcomes in the United Kingdom.⁸ The Society of Cardiothoracic Surgeons has been collecting surgeon specific activity and mortality data since 1996. These raw data are not stratified according to risk. Using 99.99% confidence intervals broadens the acceptable range considerably, but this is a sensible first step as it ensures that surgeons who operate on high risk patients are not penalised. Keogh et al rightly say that this initiative can help to reassure us about patients' safety but cannot help patients to make a choice. Then what can?

What is the purpose of coronary artery bypass graft surgery? It provides symptomatic relief to and improves the quality of life of patients with coronary artery disease, and it can increase survival in certain anatomical patterns of disease. The ideal test of a good operation would be long term survival benefit and improvement in quality of life. However, these markers are unlikely to be measured for individual surgeons and hospitals in a way that can help produce relevant and timely reports. The proportion of patients receiving multiple arterial conduits could be used as a surrogate marker for long term superior outcomes.

In the future cardiac surgical outcomes must be risk stratified and include mortality and postoperative morbidity as outcome measures. Reports should include the number of operations performed with and

without the off-pump technique and the number of patients receiving multiple arterial conduits. Keogh et al question whether publishing a list of names is important. Perhaps not in its current form, as shown in figure 1 in the article by Keogh et al, but preparing a report card with the details suggested here will act as a spur like no other to improve the quality of coronary artery bypass graft in the United Kingdom.

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People with intellectual disabilities

Their health needs differ and need to be recognised and met

People with intellectual disabilities comprise about 2% of the UK population. Demographics are, however, changing and the population of people with intellectual disabilities increased by 53% over the 35 year period 1960-95, which equals 1.2% per year.¹ A further 11% increase is projected for the 10 year period 1998-2008. These changes are the result of improved socioeconomic conditions, intensive neonatal care, and increasing survival. The health needs of people with intellectual disabilities have an impact on primary healthcare services and all secondary healthcare specialties.

People with intellectual disabilities experience health inequalities compared with the general population. Although their life expectancy is increasing, it remains much lower than for the rest of the population.²⁻⁵ The standardised mortality ratio has been found to be 8.4 for people with severe intellectual disabilities in United States and 4.9 for people with intellectual disabilities of all levels in Australia.^{4,5} Additionally, people with intellectual disabilities have higher levels of health needs than the general population,⁶⁻⁹ and these are often unrecognised and unmet.^{6,10,11} This contributes to ongoing health inequality, chronic ill

health, and premature death. Many biological, psychological, social, and developmental factors, as well as life experience, contribute to this inequality. People with intellectual disabilities also experience access barriers in using health services.¹²

People with intellectual disabilities have a different pattern of health need. For example, epilepsy, gastro-oesophageal reflux disorder, sensory impairments, osteoporosis, schizophrenia, dementia, dysphagia, dental disease, musculoskeletal problems, accidents, and nutritional problems are all much more commonly experienced.¹² Conversely, health problems related to smoking, alcohol, and use of illegal drugs are uncommon.¹² Some problem behaviours, such as self injury and pica, are specific to intellectual disabilities and may be associated with particular genetic syndromes. The commonest causes of death also differ.¹² For the general population, the leading cause of death is cancer, followed by ischaemic heart disease, then cerebrovascular disease. For people with intellectual disabilities, respiratory disease followed by cardiovascular disease related to congenital heart disease are the leading causes of death, with cancer ranked lower. Their pattern of cancers is also different, with lower rates of

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lung, prostate, and urinary tract cancers, and higher rates of oesophageal, stomach, and gall bladder cancer and leukaemia.¹²

Reducing health inequalities has been the focus of policy. However, current strategies are based on the health needs of the general population. As the pattern of health need and causes of death differ for people with intellectual disabilities, most current policies and public health initiatives will widen rather than close the health inequality gap.

This is not the only group to experience health inequalities. For example, people from ethnic minorities or those living in poverty or areas of social deprivation also experience inequality. Some needs may be relevant across groups, such as improving accessibility of services. However, the extent of inequality is greater for people with intellectual disabilities than for other excluded groups, as shown by their standardised mortality ratio. This combined with the markedly different pattern and spectrum of health need (rather than just the excess of unmet health need) indicates a requirement for specific action. This may entail redistribution of finite healthcare resources and difficult decisions regarding competing interests.

Developing guidelines can improve health by influencing policy, commissioning of services, and practice. However, guidelines can also unintentionally increase health inequalities.¹³ The amount of evidence relating to people with intellectual disabilities is less than for other groups, hence relevant issues are unlikely to be selected for development of guidelines. Assumptions are made that reports or guidelines apply to all members of the population, but panels are unlikely to have included expertise on the differing health needs of people with intellectual disabilities. Hence everyone benefits except people with intellectual disabilities. Similar unintentional discrimination can be found throughout the NHS in the United Kingdom.¹² Further discrimination in Scotland is caused by the Adults with Incapacity (Scotland) Act 2000. This prohibits research with adults who do not have capacity to consent unless their nearest relative or welfare guardian consents, but almost no one has a welfare guardian, and many adults with intellectual disabilities have no contact with a relative.

These inequalities and discrimination exist despite legislation explicitly outlawing discrimination—for example, the Australian Disability Discrimination Act 1992, the Americans with Disabilities Act 1990, the UK Disability Discrimination Act 1995, and the Human Rights Act 1998. These laws require services to make reasonable adjustments and accommodations. How-

ever, the reality is that legislation does not yet seem to have translated into improved health status for people with intellectual disabilities.

We need to change these inequalities. High quality research needs to be supported to develop the evidence base. We need to ask obligatory questions during the development of every piece of work. “How might this affect specifically people with intellectual disabilities?” “Could it possibly disadvantage some people with intellectual disabilities?” “What additional supports or reasonable adjustments are required so that it equally benefits people with intellectual disabilities?” Additionally, the population with intellectual disabilities requires specifically targeted public health interventions.

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Access to high cost drugs in Australia

Risk sharing scheme may set a new paradigm

The Australian pharmaceutical benefits scheme provides universal subsidised access to a wide range of medicines (www.health.gov.au/pbs/). Consumers make a co-payment of \$A23.70 (£8.90; €13.50) per prescription (\$A3.80 for patients who get concessions) for medicines that cost the government more than this amount (and pay in full for medicines

that cost less than \$A23.70). Prescription medicines are assessed by the Pharmaceutical Benefits Advisory Committee, which evaluates incremental cost effectiveness (including quality adjusted life years) of the prod-