

Child mental health: who is responsible?

The labelling of all childhood ills as mental health problems diverts doctors into child welfare work that is more properly the province of social services or education, argues child psychiatrist Robert Goodman. The result, he claims, is that many children who could have benefited from medical assessment and treatment for their emotional and behavioural problems do not get that help. We asked another child psychiatrist, an educational psychologist, and a social worker to respond to Dr Goodman's challenge.

An overextended remit

Robert Goodman

Parents and teachers are seriously dissatisfied with the behaviour of many children. Other children experience considerable stress, misery, or anxiety. Epidemiological studies suggest that roughly 20% of all children and teenagers are maladjusted or distressed,¹ with some estimates being substantially higher.² In the child psychiatric literature and government strategy documents these maladjusted and distressed children are referred to as having psychiatric disorders or mental health problems.^{3,4} I believe that this medicalisation of all maladjustment and distress is a serious "own goal" for the health service, generating unrealistic expectations of what child mental health services can deliver and diverting health professionals from their areas of expertise.

The medicalisation of maladjustment and distress is enshrined in the contemporary psychiatric classifications of the World Health Organisation and the American Psychiatric Association.^{5,6} Perhaps both these classifications were overinfluenced by the World Health Organisation's otherworldly definition of health as "a state of complete physical, mental and social wellbeing, and not merely the absence of disease and infirmity"; falling short of this ideal is then a lack of health, and it is only a small step to define any serious shortfall as a disease. Cynics will also note that the medicalisation of maladjustment and distress generates employment for doctors and persuades health insurers to foot at least some of the bill. An overinclusive notion of child mental health may have encouraged health providers to fill the vacuum as successive funding crises have led social services and education to withdraw from much of their traditional child and family guidance work.

Conduct disorder

The folly of an overextended medical model can be illustrated with reference to conduct disorder, which is one of the commonest of the currently recognised psychiatric disorders of childhood and the one that probably accounts for the bulk of referrals to most child mental health services. Children with conduct disorder (including oppositional-defiant disorder) are naughty,

awkward, disruptive, aggressive, and antisocial. I find it hard to see why this constellation is any more deserving of recognition as a psychiatric syndrome than love sickness, abrasiveness, or miserliness. Though conduct disorder is clearly a major problem for parents, teachers, and society in general, and though many of these children and their families need and deserve help, I do not believe that the problem is best seen as a mental health problem or that the help should usually come from the health service.

As citizens and doctors we should be concerned about conduct disorder in the same way that we are concerned about dangerous driving, homelessness, shoplifting, absenteeism, starvation, unemployment, or war. Take dangerous driving, for example. Doctors can sometimes identify predisposing medical causes such as dementia or hemianopia, and doctors are often confronted with the medical consequences of road accidents; yet no one would suggest that dangerous driving is a medical disorder per se or that the health service should take the lead in its detection and treatment.

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Antisocial behaviour in adults is usually seen as a social problem: similar behaviour in children is often categorised as a mental health problem

In my view the same applies to conduct disorder: it sometimes stems from recognisable medical syndromes or has medical consequences but it is not a medical disorder. It is a social and educational problem that often has no identifiable health component. Social services and the educational system should share the responsibility for tackling conduct disorder. Social services have statutory roles in the management of severe parenting problems and juvenile delinquency. Since conduct disorder often stems from parenting problems and often leads to juvenile delinquency, social services should take the lead in assessing and managing conduct problems. Schools also have a key role to play since many children have conduct problems that are most evident in the classroom and playground, often reflecting school factors such as a *laissez faire* attitude to bullying or a failure to meet the needs of children with dyslexia or other learning difficulties.

Sharing the responsibility for treating a particular disorder between many agencies is all too often a recipe for proliferating meetings and diminishing action; the interests of children with “pure” conduct disorder would be better served if health bowed out. Social services and education need to be adequately staffed and funded to provide effective interventions such as parent training and school based programmes. This will leave child mental health services better placed to provide supplementary input for the minority of children whose conduct disorders have antecedents (such as hyperkinesia) or consequences (such as severe depression) that call for the special expertise of health professionals.

Empire building and decolonisation

Large areas of child welfare work have been inappropriately annexed into the medical empire; a planned decolonisation is long overdue. Beware of the tendency to assume that the “natives” cannot manage their own affairs. Who says that social workers or educational psychologists could not take over much of the work currently carried out by mental health professionals? With the empire gone, what will be left? There is a need for debate here, but even the most ardent decolonisers are likely to see a major continuing role for the health service in assessing and treating some varieties of child-

hood maladjustment and distress, including hyperkinesia, autism, obsessive-compulsive disorder, schizophrenia, and anorexia nervosa—though some of these disorders could arguably be labelled as developmental rather than mental health problems.

Children with these disorders need the sorts of input that only health service professionals are likely to provide. At present, many such children go undiagnosed and untreated, perhaps because limited health service resources have been diverted into general child welfare work. Proved treatments such as the use of medication for hyperkinesia or the use of behavioural therapy and medication for obsessive-compulsive disorder are greatly underused.^{8 9}

Some caveats

My position could be misunderstood in several ways. While I believe that the money spent on helping maladjusted and distressed children could be used more effectively, I am arguing for a redeployment rather than a reduction in funding. Indeed, I would favour an increase in funding. Though medical imperialism needs to be reversed, decolonisation should not be instant; social services and education would obviously need enough time to train the necessary staff. Finally, I am not suggesting that the boundaries of the health service could ever be drawn once and for all: these boundaries will shift repeatedly as new treatments emerge and society's expectations change.

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Commentary: Child mental health services are not medical empires

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As child mental health clinics round the country develop longer and longer waiting lists it is tempting to suggest ways of helping children in other settings so that overextended specialist staff can concentrate on specific complex disorders. If additional resources were made available to local authorities so that children with conduct disorder could receive input to improve their behaviour early in childhood, professionals, parents of affected children, and society as a whole would be delighted. Specialist education staff

could help teachers in managing children more effectively using behavioural programmes in mainstream classes or in small groups. Social workers might be able to provide family therapy and behaviour therapy to help parents manage behaviour effectively rather than concentrating on child protection work, accommodating children, or programmes for delinquents. This preventive rather than palliative approach is advocated by the Department of Health.¹

Loss of specialist resources

Unless increased funds are made available, Dr Goodman proposes that mental health staff, but not child psychiatrists, should be redeployed in local authority settings. This has already happened round the country with the transfer of social workers and to a lesser extent education staff from child mental health teams into generic local authority teams.

Unfortunately this has not led to improved treatment in these settings because it has coincided with and is related to the loss of specialist resources, especially in education, due to generalised reductions in public expenditure. In any case many specialist staff find it difficult to work in relative isolation in front line settings² without the ongoing training, support, and ready consultation available in a multidisciplinary team.

Exacerbated by increasing pressures on children from poverty, unemployment, single parenthood, and parental conflict, the net result has been increased demand for access to specialist child mental health services and concern about long delays for appointments even for serious urgent cases. The pressure is generally greatest for those cases which should be seen by an experienced child psychiatrist.

Medical empires? Child mental health services are fortunate if their funding reaches 5% of that of adult services, most likely only if there is a local inpatient service. A comparatively well resourced service such as my own has 23 whole time equivalent professional staff, including five local authority social workers, serving a multiply deprived borough which has 50 000 children and over 100 schools. Our resources are not easily shared out. Child mental health staff, apart from child psychiatrists, are no better paid than other social workers, educational or community psychologists, health visitors, or teachers unless they also have managerial responsibilities.

Need to see a range of cases

Child psychiatrists, especially in inner city areas, are much in demand for the assessment and management of psychosis, severe depression, complex developmental disorders, psychosomatic disorders, severe physical trauma, chronic illness, eating disorders, hyperkinetic syndrome, and child care assessments for the courts. We do see highly selected children with severe or intractable conduct disorders, and our experience and broad training are well used in integrating aspects of



Lord of the Flies: conduct disorder or a social problem needing a social solution?

neglectful or abusive parenting, constitutional factors such as learning difficulties, hyperkinetic syndrome, and attachment. We may provide advice about placement and sometimes offer treatment.

I consider severe conduct disorder an important mental health problem, and our understanding of its origins and treatment and of forensic adolescent psychiatry all require urgent development. Resources focused on young children in child psychiatry as well as in local authority services may pay dividends in reducing harm to society and the cost of imprisonment.

Experienced non-medical staff are also fully stretched with the relentless increase in referrals of children with severe or multiple problems. Mild cases? There are a few and we are glad when the referrals come in. Otherwise how can we train junior medical staff and trainees in psychology, nursing, and social work, who will mostly work in local authority or community settings. It is essential that their training is broad so that they are familiar with the range of problems, minor and severe, and variety of treatment modalities. Some will go on to work in child mental health services, from which they will provide consultation and support for professionals in other settings, assessment and treatment for severe and complex cases, and training.

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Commentary: The medical model is unhelpful

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Though late in the day, Robert Goodman's article is welcome from an educational psychologist's perspective. The medical model has been the bête noire of the psychology profession for two decades. The phrase "medical model" characterises a way of thinking that identifies children who worry their teachers and parents as having something wrong with them that requires treatment. This treatment may range from

medicine to therapy. The acceptance of therapy as medical treatment itself raises interesting questions. It results from the historical and now popular connection between psychiatry and mental states. A more fundamental question is how far psychiatry itself fits the medical model.

It is vital to distinguish between the social arrangements that are made for assessing and helping worry-

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ing children and their parents and teachers and the ways of thinking used to understand the children. Robert Goodman seems to mix these together. Making a distinction between mental health professionals and social services and education is not the same point as the medicalisation of children's difficulties. The former is about social organisation, the latter about models or paradigms. Mental health professionals include clinical psychologists, psychotherapists, and family therapists. These professions use a wide range of models and share with educational psychologists concerns about the overextension of the medical model. Clinical psychologists, for example, will have important work to do with many "conduct disordered" children even when the full force of Robert Goodman's argument is accepted.

Medical model is simpler to apply

The main difficulty with the medical model from a psychologist's point of view is that even though the origin of the problem is a worry expressed by another individual—that is, it has a social origin—the focus shifts immediately to the child as a totally separable entity. As with the medical model generally, all the attention is concentrated on a "fault" of some kind in this entity. A firm boundary is drawn around the problem and around the individual child.

Psychological, and even more fundamentally, social models continue to locate the child in a social context that has its own history. This makes it harder both to understand the child and to work out what to do to help him or her. The medical model is simpler to apply and raises quickly the possibility of a "treatment" or course of action.

Psychological and social models raise questions and challenges for parents and teachers and widen the search for factors. Parents and teachers can become uncomfortable with this process and retreat to the safety of the medical model. The pursuit of the diagnosis of attention deficit hyperactivity disorder is vivid illustration of this. As an educational psychologist I find it interesting that Robert Goodman reserves this field through his use of the term hyperkinesis. In my



Conduct disorder or an educational problem needing an educational solution?

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experience it is one of the most difficult explanations to test out and establish, and the ease with which doctors are currently applying it, with the magic prescription of methylphenidate to follow, is the worst current example of the medicalisation of children's behaviour.

Models for understanding children's development are not in competition with each other. They compete only at the point of application to any particular child. Understanding and helping children is fraught with difficulties. Cooperation, communication, and flexibility between all the professionals involved is required. Though it is true that the medical model is over-extended, this does not mean that we retreat to our professional bunkers.

Commentary: Ordinary misery should not be mistaken for pathology

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I find myself in broad agreement with many of the propositions in Robert Goodman's paper. In fact, my former colleagues in a child and adolescent mental health service became wearily accustomed to my repeated, and often heated, references to "the psychiatrisation of everything." Dr Goodman is right to point out that studies suggesting that 20% of all children are "maladjusted or distressed" can only be reflecting the trend for ordinary (and usually transient) misery to become steadily pathologised.

However, I must take issue with Dr Goodman over some of his assertions and over his rather unrealistic

action plan. Firstly, he argues that child psychiatrists should concentrate on a range of clinical syndromes and should extricate themselves from messy (and unresponsive) "conduct disorders" in particular. However, this would be achievable only if a person other than a psychiatrist could confidently and unproblematically differentiate between those conduct disorders which stem from, or coexist with, recognisable medical syndromes and those which do not. Moreover—and this is the difficult bit—if they were to avoid complaints, litigation, and other undesirable consequences of being seen to have acted *ultra vires*, such persons

would need a clear mandate to make these decisions. They would need to be recognised as competent to adjudicate on the boundaries between disorder, as it is currently defined, and extreme forms of ordinary distress.

Difficulty of distinguishing between the normal and the abnormal

Secondly, Dr Goodman argues that “there is good reason for social services to take a leading role in the assessment and management of conduct problems.” I think that social services departments would be surprised to discover that they do not currently do so. Many young people who display behaviour congruent with (the catch all) diagnosis conduct disorder are accommodated by the local authority, or have come to their attention via education or some other referral route. The problem is that conduct problems are notoriously difficult for anyone to deal with. “Parent training” or “school based programmes” look like fine ideas—if only it were that simple. Moreover, parents, foster carers, and residential staff are often alarmed by the violent outbursts and the threat of self harm associated with conduct disorders.

This inevitably draws child psychiatrists into the fray, as they are asked to screen for depression or other mental disorders. I agree with Dr Goodman that in many cases this is a waste of everyone’s time, but it will continue to be standard practice as long as psychiatrists hold the professional mandate to differentiate between the normal and the pathological. I am sure that this would be relinquished very reluctantly, and perhaps inappropriately, by the profession.

Clearly many professional groups, social workers among them, have been hoist by their own petard in claiming the ability to effect change, or predict dangerousness, in all manner of situations in which causation is difficult to establish and effective interventions virtually non-existent. Thus, while I applaud Goodman’s point about an increase in resources (adequate nursery provision would be very handy), a treatment oriented approach to conduct disorder often simply does not work, whoever is delivering the service. Child welfare agencies know this, which is why nobody wants to take the primary responsibility for this group of young people, although it is social services who often have to manage their containment.

Primary care—opportunities and threats

Developing professional knowledge: Making primary care education and research more relevant

Pauline Pearson, Kevin Jones

Summary

The trio of recent government white papers heralds a new world for primary care. Many changes in the education of future primary health care professionals and in the research ethos of the discipline will be needed to realise this vision. New skills and attitudes, not least in multidisciplinary working; lifelong learning; and greater understanding of and participation in primary care research will have to emerge from educational efforts in the next few years.

Background

The government’s ambition is for a high quality, integrated health service which responds to the health needs of individual patients sensitively and cost effectively.¹ The white paper *Primary Care: Delivering the Future* offers a range of suggestions for developing professional education and research in primary care so that such a service can be realised,² and *Primary Care: Choice and Opportunity* provides the framework for these developments.³ In this article we ask: how ready is primary health care to respond to this vision for the future? In particular, what are the opportunities and threats for education and research inherent in these proposals?

Five important themes have been highlighted (box). Underlying these themes is the need to integrate development and thinking about research, clinical audit, clinical guidelines, and professional education.

Research and development

The government wants a more research based primary care service; it is trying to encourage primary care professionals to see participation in research as a welcome necessity in higher professional training. *Primary Care: Delivering the Future* promises new opportunities for primary care practitioners to be involved in research and development; new collaboration between the government, the NHS, universities, and professions to promote primary care research; a new funding system and an at least doubled budget for research; an extension of primary care research networks to all regions; and support for wider non-medical involvement in primary care research and development. These are laudable aims. How ready is primary care to meet this challenge?

Evidence based practice in primary care is in its infancy, with small numbers of researchers and academics supplying much of the knowledge base. Many important issues need researching in primary care, particularly the epidemiology and best treatment of those common illnesses that are seen almost exclu-

This is the sixth of a series of articles discussing the imminent reforms in primary care

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sively outside hospital. The recent interim report from the National Working Group on Research and Development in Primary Care stated that there was “an urgent need to expand the research capacity in primary care from its present low base.”⁴ Five areas needed attention: the range of content of primary care research, the methodological quality of research, the availability of research leadership, the number of non-medical clinical staff with research expertise, and the involvement of non-clinical researchers.

Support for research

Service based researchers need continuing support. Several methods of support have been suggested as effective, but most are time consuming. As well as individual mentors within the workplace (usually with an academic link), some regions have experimented with additional posts to support primary care research or health services research in general. Such posts typically employ one person with research skills who performs research and facilitates the research of colleagues. “R&D” support for providers, previously known as Culyer funding,⁵ may shift the provision of such infrastructure towards primary care but this will take time and determination.

Researchers may also derive support from universities and postgraduate establishments through short courses and higher degrees at both masters (MSc, MPhil) and doctoral (MD, PhD) levels. But often publicity about courses is not coordinated, leading to duplication of provision rather than choice. Time and geography may also prevent many primary care practitioners from using these opportunities. More flexible approaches—involving part time study, distance learning, and credit accumulation—must be considered. Practitioners may also feel that the academic context of courses is difficult to relate to the realities of everyday practice. Those providing training in research methodology must therefore ensure its relevance to the needs of practice and community based researchers as well as to the requirements of the established academic community.

Peer support groups ranging from networks of local researchers to “MD clubs” are active in many

Themes highlighted in white papers on primary care^{1 2}

- More education and training should be multidisciplinary, in order to promote effective multidisciplinary working
- There should be more opportunities for health professionals to train in primary and community care settings
- Continuing education should meet the needs both of primary care staff and the service
- The research and development base in primary care should be strengthened
- Clinical audit in primary care should be further developed

parts of Britain. Networks in primary care have tended to consist of general practitioners working on a wide range of research topics in the same geographic area. Networks can, however, be organised in several different ways—by discipline (general practitioners, community nurses, professions allied to medicine); by interest area (asthma, diabetes); by method (clinical trials, qualitative methods); or by geography. There is a pressing need to explore the most effective form of networks and both promote and support their use in primary care (AP Hungin, conference on research networks for primary care, Durham, 1995).

Education and training for practice

Preparation for professional practice in the community builds on the foundation of initial education. Basic education in both medicine and nursing has changed considerably in recent years. The *Tomorrow's Doctors* report⁶ prompted undergraduate medical curricula which focus on strategies for lifelong learning and community based teaching.^{7 8} Nursing has been changed both by the introduction of Project 2000 diploma courses, which centre on health rather than illness,⁹ and through increasing moves into higher education. The people entering preparation for professional practice in the community are therefore not a static group. Change is continuing, and they will have different learning needs as time goes on.

General practitioners

The role of the general practitioner will probably change as much in the next 25 years as in the past quarter century. Increasingly, general practitioners need generic and transferable skills in clinical, interpersonal, and management work and in information technology. They must be confident in delegating work and able to work effectively with an ever expanding network of colleagues from a variety of disciplines and agencies. In undergraduate education, debates about what is core training and what is optional sometimes obscure the real challenges: developing genuinely transferable skills and ability in handling change.

Salaried or not, general practitioners will need to be prepared to be proactive and able to deal with change. General practitioners in the future will have to develop their ability to assess the health needs of populations and communities¹⁰ and draw on a range of statutory and voluntary health and social care agencies to meet those needs. Above all, practitioners will need



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to draw on—and indeed add to—research evidence, which should inform practice. Continued change in undergraduate programmes is required.

Primary care nurses

Building on Project 2000,⁹ community nurses are, increasingly, able to train to degree level. In addition, the new white papers make clear the potential for nurses to explore the boundaries of their existing practice. Though the debate about advanced practice continues, the notion of the nurse practitioner (despite its ambiguities¹¹) is alive and well. Recent changes have diluted training for specialist community nursing, however, with reductions in curricular time and increased teaching in the practice setting. Although community nursing research is growing, skills remain thinly spread. Community nursing courses for the future will enable nurses to act more autonomously and to fulfil their widest potential. Community nurses will need robust skills for critical appraisal of the relevant literature and to contribute to the development of new knowledge through research.

In general practice, vocational education and research have historically been largely separate, beginning to come together substantially only in recent years. For both doctors and nurses, and for other practitioners in primary care, skilled practitioners must be attracted into teaching, so that the enthusiasm with which they aim to develop good quality, evidence based care can be shared with those seeking to enter primary care practice. To achieve this, practice teaching needs clear standards and better remuneration that reflects the value attached to this role.

Continuing development in practice

Four key strands could help primary care professionals to continuously develop skills and knowledge and thereby ensure continuing high quality care.

Firstly, each practitioner should be looking at practice systematically and asking: what am I trying to achieve? what should I be doing to achieve it? am I doing what I ought to be?—essentially, the audit questions. This process of reflection will be enhanced by examining practice with colleagues.

Secondly, practitioners must continue to review their learning needs, and access appropriate opportunities to meet these, whether through taught courses based in higher education (diplomas, masters degrees), resource centres,¹² or debate and discussion through professional organisations. There needs to be a considerable shift, both in higher education and in professional organisations, towards a culture which supports lifelong learning. In higher education this may mean moving to funding systems which value post-qualification teaching for professionals. For professional organisations, the primary challenge is to help practitioners to move away from a defensive stance, where change is always seen as a threat, towards a more proactive and creative approach.

The third strand should be the development of a culture within primary health care teams or organisations which achieves jointly held aims for patient care.¹³ The current focus of doctors and nurses on individual learning and, often, on getting postgraduate education

credits must shift towards achieving integration of effective services for the practice population.

Finally, teams and individuals should learn within the wider policy context, looking towards the skills and knowledge they will need next year or the year after and towards the challenges they will need to meet. In this way they will set agendas for research and development for the future.

Academic primary care: still underdeveloped

Ideally, more service general practitioners should participate in research. But most will look to academic departments for support, and not all will find what they need.

Academic departments of general practice and primary care are relatively new—the universities of Oxford and Cambridge got round to creating chairs only in 1996. Primary care staff should be worried as some of those gaining senior academic positions have been thwarted in their research efforts by the pressures of teaching, administration, and clinical work and do not have the higher degrees and research experience long considered essential by hospital based departments. Furthermore, at least one chair has been advertised recently and not filled. There is not a large pool of senior academics ready and willing to take on these posts, and some existing departments of academic primary care are struggling alongside the better established and resourced hospital academic units.

The recently published research assessment exercise (http://www.niss.ac.uk/education/hefc/rae96/1_96/t02.html), which considered community based clinical subjects in general rather than primary care in particular, reported on research performance in this field in 35 universities in Britain. The government's wish to have a centre of research excellence in primary care in each region is not well supported by the results: on a scale of 0 to 5* there were two 5* departments (Oxford and Cambridge—but remember what was said above), three 5s in London and one in Cardiff, and six 4s. Sixteen departments in undergraduate medical schools got grades of only 3a or 3b.

Academic primary care has enough on its plate with reforming undergraduate curricula and battling to maintain (and increase, if possible) research portfolios. General practitioner academics are also having pressure put on them by the Medical Practices Committee to ensure that they fulfil the required service commitment. Where does providing a stimulus to service based research fit in here?

Flexibility is the key

The primary care community may expect academic departments and similar institutions to provide a lead in education and research, but this might be difficult if new resources are not used appropriately. In return for more funding, however, academics must be willing to be flexible and respond to the changing needs of the NHS. They must help service practitioners as well as fellow academics to integrate learning and research into their everyday work; only then will the necessary knowledge and skills diffuse through the whole of primary care.

We thank Brian McAvoy, John Spencer, and Tim van Zwanenberg for their helpful comments on earlier versions of this paper.

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The rationing debate

Rationing health care by age

The case for

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Age is an appropriate criterion for choosing which people who could benefit from health care should be offered it

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As we grow older our recuperative powers diminish. Thus we accumulate a distressing collection of chronic incurable conditions. Some of these are no more than a minor nuisance, and we adapt as best we can; and when adaptation is not possible we learn to tolerate them. Some are more serious, involving severe disability and persistent pain, and may eventually become life threatening.

We are also at risk of various acute conditions (like influenza or pneumonia) which are more serious threats to the health of elderly people than to younger people. We also have more difficulty recovering from what younger people would regard as minor injuries (such as falls). When you add to all this the increased likelihood that illness (and other disruptions of our normal lifestyle) will leave us rather confused and in need of more rehabilitative and social support than a young person it is hardly surprising that NHS expenditure per person rises sharply after about age 65.

The vain pursuit of immortality

People are also living longer, and people aged over 65 now form a much bigger proportion of the population than they used to. From the viewpoint of NHS expenditure this would not matter if the extra years of life were predominantly healthy years but it would if the extra years were ones of disability, pain, and increasing dependence on others.

■ *“This vain pursuit of immortality is dangerous for elderly people”*

The evidence on this is ambiguous. Many people remain fit and independent well into their 80s. Others enter their 60s already afflicted with the aftermath of stroke, heart disease, arthritis, or bronchitis. It is not clear whether things are getting worse at each year of age, or whether expectations are rising and people are now more likely to report disabilities once shrugged off as the inevitable consequence of getting old. That

many of these conditions are incurable does not mean they are untreatable. Much can be done to reduce their adverse consequences, including many remedial activities which lie outside the NHS (such as home adaptations, domestic support, and special accommodation).

It is important to get away from the notion of “cure” as the criterion of benefit and adopt instead measures of effectiveness that turn on the impact of treatments on people’s health related quality of life. Such an approach concentrates on the features that people themselves value, such as mobility, self care, being able to pursue usual activities (whatever they are), and being free of pain and discomfort and anxiety and depression.

Improving the quality of life of elderly people in these ways may not be very costly, but these unglamorous down to earth activities tend to lose out to high tech interventions which gain their emotional hold by claiming that life threatening conditions should always take priority. This vain pursuit of immortality is dangerous for elderly people: taken to its logical conclusion it implies that no one should be allowed to die until everything possible has been done. That means not simply that we shall all die in hospital but that we shall die in intensive care.

Reasonable limits

This attempt to wring the last drop of medical benefit out of the system, no matter what the human and material costs, is not the hallmark of a humane society. In each of our lives there has to come a time when we accept the inevitability of death, and when we also accept that a reasonable limit has to be set on the demands we can properly make on our fellow citizens in order to keep us going a bit longer.

It would be better for that limit to be set, with fairly general consent, before we as individuals get into that potentially harrowing situation. When the time comes we shall probably each want an exception made in our case, because few of us are strong willed enough to act

The BMJ, BMA, King's Fund, College of Health, and RAG (Rationing Agenda Group) will be holding a conference entitled “Rationing in the NHS: Time to get real” on 10 and 11 July at Kensington Town Hall. For further information ring Jane Lewis 0171 383 6605 (Email: 106005.2356@compuserve.com).

cheerfully in the general public interest when our own welfare is at stake. But if a limit is to be set, on what principles should it be determined? And what is their justification? And what role does age have?

In arguing for this article's proposition I have sought to make two contextual points clear: firstly, that ability to benefit should be measured in rather broader terms than cure or survival, and, secondly, that although chronological age is the best single predictor of increasing health problems, it is only a predictor, not a mechanistic determinant.

But age as an indicator of declining recuperative powers, of future health problems, of increasing need for health care, and of declining capacity to benefit from health care (because of shorter life expectancy) is only half the story. It addresses the issue of whether age is a good indicator of the extent to which people could benefit from health care but not in itself of whether they should be offered it. This more crucial step depends on what the objectives of the NHS are to be.

The NHS's objectives

If we start with the proposition that the objective should be to improve as much as possible the health of the nation as a whole then the people who should get priority are those who will benefit most from the resources available. In some cases the old will benefit most, in others the young. But for treatments which yield benefits that last for the rest of a person's life (or for a long time) the young will generally benefit more, because the rest of a young person's life is usually longer than the rest of an old person's life. And even among old people themselves the life expectancy of a 70 year old is usually greater than that of an 80 year old. Where a treatment offers only modest benefits a person may have to live a long time to make treatment

worth while—that is, to make the benefit to that person larger than the sacrifices of rival candidates who failed to get treated. So improving the health of the nation as a whole is likely, in some circumstances, to discriminate indirectly against older people.

Is this morally defensible? Well, if we behaved otherwise we would by implication be asserting that in order to provide small benefits for the elderly, young people should sacrifice large benefits. What makes old people more deserving of health benefits than young people? One argument might be that all their lives they have been paying their taxes to finance the health care system (among other things), and just when they need health care most the government lets them down. But the government—that is, their fellow citizens—did not promise to do everything possible no matter what the costs.

The NHS is part of a social insurance system, not a savings club for each individual's health care expenditures. It is the lucky ones who do not get their money's worth out of the system, and the unlucky ones who need heavy NHS expenditures all their lives. The NHS is there to meet certain contingencies but not others. And many of the treatments which the NHS now offers to old people in certain contingencies were not even invented when they started contributing 40 or 50 years ago. So to argue, from a historical viewpoint, about an entitlement to get your money's worth seems inappropriate to any insurance scheme, and in particular to a social insurance scheme such as the NHS.

■ *"The values of the citizenry as a whole must override the values of a particular interest group within it"*

A different line of argument might be that as the number of years left becomes smaller and smaller, each is more precious. The implication of this argument is that elderly people value their small improvements more highly than young people do their much larger improvements. This raises a fundamental problem about whose values should count in a social insurance setting. Suppose that it were true that older people would spend relatively more on health care to get health improvements rather than other things, whereas younger people would spend relatively more on (say) education for their children and rather less on health benefits for themselves. Rational self interest drives individual citizens operating in private markets precisely in that direction.

But did we not take the NHS out of that context precisely because as citizens (rather than as consumers of health care) we were pursuing a rather different ideal—namely, that health care should be provided according to people's needs, not according to what they were each willing and able to pay. A person's needs (constituting claims on social resources) have to be arbitrated by a third party, whose unenviable task it is to weigh different needs (and different people's needs) one against another. This is precisely what priority setting in health care is all about. So the values of the citizenry as a whole must override the values of a particular interest group within it.



SIMON STERN THE INKSHED

A fair innings

So I can find no compelling argument to justify the view that the young should sacrifice large benefits so that the old can enjoy small ones. But I can find an argument which goes in the opposite direction. It is that one of the objectives of the health care system should be to reduce inequalities in people's lifetime experience of health. The popular folklore is rich in phrases indicating that we all have some vague notion of a "fair innings" in health terms. Put at its crudest, it reflects the biblical idea that the years of our life are three score and ten. Anyone who achieves or exceeds this is reckoned to have had a fair innings, whereas anyone who dies at an earlier age "was cut off in their prime" or "died tragically young." As has been observed, while it is always a misfortune to die if you wish to go on living, it is both a misfortune and a tragedy to die young. Why?

From my perspective (approaching the age of 70) I see clearly why it is a tragedy, because someone who dies young has been denied the opportunities that we older people have already had. If reducing inequalities in lifetime health is a worthy social objective, it will lead us to be willing to do more to enable young people to survive than we are willing to do to enable old people to survive.

But I do not think that the notion of a "fair innings" should be restricted to matters of survival and life expectancy. Quality of life considerations concerning health may be just as important. Someone who has suffered a lifetime of pain and disability cannot be said to have had a fair innings even if she did live to be 80, and I would therefore extend the concept to embrace something more than just years of life. My preferred concept would be the number of quality adjusted life years a person had enjoyed. On the whole people's earlier years are healthy years, and their later years less healthy years, so this does not affect the general tenor of my argument. What it implies is that we need to consider, alongside age itself, the quality of a person's lifetime experience of health. The worse it has been, the more consideration they deserve, age for age.

Age matters

So my overall conclusion is that age matters in two respects. Firstly, it affects people's capacity to benefit, and therefore places them at a general disadvantage if

the objective is to maximise the benefits of health care. Secondly, the older you are the more likely you will have achieved what your fellow citizens would judge to have been a fair innings, and this will place old people at a disadvantage if the objective is to minimise the differences in lifetime experience of health. I would be the first to admit that I personally have had a fair innings and that it would not be equitable to deny a younger person large benefits in order to provide small ones for me. Indeed, I would go further: it would be equitable to provide small benefits for a young person even if by so doing I were denied large benefits, provided that the young person in question had a low probability of ever achieving a fair innings. Note that this argument does not mean that benefits to young people take absolute priority over benefits to old people. It simply means that we give rather more weight to them than to us.

Surveys of public opinion commonly find that most people, if pushed into a tight situation, would give priority to the young over the old when distributing a given amount of health care benefit. There is also little doubt that health care professionals share this general attitude. It does not, of course, stop them from being kind, considerate, and caring when old people need health care, but it manifests itself at the level of clinical policymaking, when different needs have to be prioritised. For the professionals what may be in their minds may be mostly old people's impaired capacity to benefit from health care. But I strongly suspect that some variant of the fair innings argument also underlies such views, and this is especially likely to be the case among the general public. When the views of older respondents in such surveys have been reported separately, they too give priority to the young over themselves.

So I am encouraged to hope that, in the interests of fairness between the generations, the members of my generation will exercise restraint in the demands we make on the health care system. We should not object to age being one of the criteria (though not the sole criterion) used in the prioritisation of health care, even though it will disadvantage us. The alternative is too outrageous to contemplate—namely, that we expect the young to make large sacrifices so that we can enjoy small benefits. That would not be fair.

The case against

J Grimley Evans

Age is an appropriate criterion for choosing which people who could benefit from health care should be offered it

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continued over

Older people are discriminated against in the NHS. This is best documented in substandard treatment of acute myocardial infarction and other forms of heart disease, where it leads to premature deaths and unnecessary disability. The care for older people with cancer is also poorer than that provided for younger patients.

Age discrimination in the NHS occurs despite explicit statements from the government that withholding treatment on the basis of age is not acceptable. Ageism is mostly instigated by clinicians but condoned by managers. Fundholding general practitioners have a financial incentive to deprive older patients of expen-

sive health care, but there is no ready way to find out whether they do so. Whatever its full extent, the documented instances of age discrimination, together with the occasional published apologia for ageism, show that the morality of age based rationing should be a matter of public concern.

Need to assess individual risk

It is important to be clear what we are talking about. It is proper for a doctor to withhold treatment or investigation that is likely to do more harm than good to a

patient. In an individual case actual outcome depends on the patient's physiological condition. The prevalence of impairments that shift the risk:benefit ratio adversely increases with age, so where individual physiological condition is used as the basis for allocating treatment older people are more likely on average to be excluded than are younger people. Nevertheless, wide individual variation exists in aging, and many people in later life function physiologically within the normal range for people much younger. The key issue, therefore, is that each decision should be made on a competent assessment of individual risk.

What I am objecting to is the exclusion from treatment on the basis of a patient's age without reference to his or her physiological condition. The patient is being treated as though he or she necessarily had properties identical with those corresponding to the average of the age group. We can draw a contrast with social class and skin colour. Should we withhold health care from members of lower social classes or from black people because of the poorer average outcome of their groups? Rather, most of us would suggest that extra attention should be paid to vulnerable members of such groups to try to compensate for their disadvantage. Why should old people not be viewed similarly?

Ethics, ideology, and the law

I am convinced that in the United Kingdom at present it is unethical to use age as a criterion for depriving people of health care from which they could benefit. The fundamental issue is ideological; and ideologies—and the ethical systems derived from them—can change with circumstances. The notion, implicit in the writings of many ethicists, that there is an objective basis for a universal ethical system is a dangerous illusion. Ethics are no more than logical deductions from primary ideologies. Ideologies are primary in the sense that they cannot be validated by any objective means. They can arise in various ways, and in England they arose by a long process of mutual adaptation of heterogeneous people developing efficient ways of living together. Not having a written constitution, we have in Britain to deduce the ideological principles of our society from our history and from the shared rhetoric of our major political parties.

From these I conclude that in times of peace British national values include the equality of citizens in their relation to the institutions of the state and acknowledgement of, and respect for, the uniqueness of individuals regardless of their physical or mental attributes. From the latter follows the equal right of all citizens to live as they wish so long as they do not impede the like rights of others. If these ideas are indeed embodied in the ideology of British society, ageism, as well as racism and sexism, will be unethical.

The founts of ageism

Exploitation of the weak

Several factors generate or are invoked to justify ageism in health care. The first is an issue of realpolitik. When health care managers aim to control costs older people are natural victims. They do not riot; they are uncomplaining and politically inactive. The threat of tactical voting by the militant elderly people of the

United States caused a major shift in health and social care resources to their benefit. Although comprising more than a quarter of the electorate in Britain, old people are not yet seen by politicians as potential tactical voters. Inevitably they suffer, and inevitably ageism remains legal.

Professional ignorance

Ageism may arise from well intentioned ignorance, where health professionals assume incorrectly that older patients will be harmed rather than benefited by treatment. In reality the absolute benefit of some treatments—in terms, say, of deaths prevented—increases with prior risk while the probability of side effects remains constant. Where prior risk rises with age such treatments may be more effective given to older people than to younger. Moreover, except in the limited area of intensive care medicine, we still know little about the physiological variables that determine individual risks of benefit and harm from medical interventions. We need more research to enable meaningful negotiation over options for care with patients of all ages and to underpin more efficient targeting of resources.

Prejudice

The most important source of ageism is prejudice. Surveys in Britain show that older people are widely seen as of lower social worth than younger, but little has been done to explore the origins and dynamics of this prejudice. Some researchers suggest that public attitudes displayed by such surveys are a valid basis for rationing in the health services. There are several problems with this facile suggestion. People answering questions in a way that indicates low valuation of older people may do so not because of what they really feel

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but because of what they think the interviewer will regard as the "right" answer.

Typically, questions are in "doctor's dilemma" format in which there is treatment available for only one of two people who differ in age. The possibility of generating equity by allocating the treatment on the toss of a coin is not usually offered and is unlikely to be thought of spontaneously by the average citizen. It is also naive to assume that attitudes exposed by the desperate situation simulated in a doctor's dilemma would also emerge in decisions on real life issues such as the relative lengths of waiting lists for hip replacements and hernia repairs.

Survey interviews are rarely confidential and do not contain control questions in which the two potential patients differ, say, in skin colour. Would researchers suggest that racial prejudice revealed by their questionnaires should be a basis for health service rationing? We may presume not; it would be recognised, as it should be for ageism, that the respondents were failing to conform to the principles of British society. To imply, as some have found it convenient to claim in the ageism debate, that it is paternalistic to esteem the values of society above the ignorant prejudices of some of its members is to confuse demagoguery with democracy.

The power of economics

Economists sometimes claim that their discipline is so fundamental that it can provide a sufficient basis for allocating society's resources in health care. Whether this assertion is acceptable or not is an ethical issue. It can be argued that economists should be restricted to identifying the most cost effective way of achieving a pattern of allocation that has been defined on ideological grounds. We have lived so long under a theocracy of markets, competition, and cost containment that people may forget that these are driven by an ideology of no more validity than the ideology behind common cause, collaboration, and social purpose that it supplanted.

Alan Williams has suggested that if allocations of resources based on quality adjusted life years (QALYs) are thought to bear too heavily on older people, their needs can be weighted to conform more closely with externally derived principles of equity. This approach has the advantage of making the ethical input both explicit and manifestly the responsibility of those who provide it. Virtue still emerges wearing what many will see as the indecency of a price tag. Williams's dialectic derives from what he sees as a necessary trade off between equity and efficiency. In my view his notion of what should be regarded as efficiency in the NHS is questionable. We can find common ground in the assertion that health care resources should be allocated so as to do the most good. The ethical argument crystallises round what view of good should prevail.

There are two perspectives on a health service. On the one side are the purveyors who, like shareholders in a chain of grocery shops, look for the best return on their investment. They may well think it appropriate to measure this return in terms of some measure such as QALYs gained. On the other are the users of the service. Although the NHS has in recent years been forced into a Procrustean bed of market imagery, the average

British citizen sees it not as a chain of grocery shops but as something more akin to a motoring organisation to which he pays a subscription so that it will be there to do what he wants when he wants it. He will judge the service on the extent to which it meets his informed desires. There is no reason to expect that maximising the production of QALYs will lead to the same recipe for distributing limited resources as maximising the achievement of users' informed wishes.

British citizens as taxpayers might see themselves alongside Williams with the purveyors but as potential patients would, I suspect, ally themselves more consistently with the users. My assessment is that the users' perspective also provides a rationale more consonant with national values and with the explicit intentions for the NHS at its foundation. There are also unacceptable implications in the purveyors' approach.

Firstly, measurement of output in units based on life years directly or indirectly puts different values on individuals according to their life expectancy. Thus citizens are no longer equal and older people in particular are disadvantaged. Secondly, it assumes that the value of life, at any given level of objectively assessed disability, is determined by its length. But if we assert the unique individuality of citizens, the only person who can put a value on a life is the person living it. Lives of individuals are therefore formally incommensurable and it is mathematically as well as ethically improper to pile weighted valuations of them together as an aggregable commodity like tonnes of coal. There have been nations whose ideologies value citizens only for their potential collective usefulness to the state as soldiers, workers, or breeding females. In the United Kingdom, at least for the time being, are we not spirits of another sort?

The "fair innings" argument

This argument asserts that we have a right only to a certain number of years of life and after then only palliative as distinct from therapeutic care should be provided. Although sometimes mistaken for an economic argument, the fair innings approach will not necessarily save money unless we apply its corollary of compulsory euthanasia at the end of the innings. Palliative care can be more expensive than therapeutic care; the money saved by not providing coronary artery surgery for an elderly woman may be spent several times over if she has to live for months in a nursing home because of her angina.

The fair innings argument has historical roots in Christian theology and its requirement for time to earn one's place in heaven by purging the sins of youth with the good works of later life. For secular man fair innings now codes for two crucially different ideas which commentators sometimes confuse. The first is that as individuals we commonly come to a time when we conclude that we have done all that we wished and were able to do and that life no longer offers the potential of interest or pleasure that might make it preferable to oblivion. For some others of us death may at a particular time offer personal meaning, climactic consummation, or a perfected symbolism to our lives. Dying for a worthy cause may seem better than survival in servitude, failure, or dishonour. Such ideas underlie the existential concept of a fair innings or natural

lifespan. Only the person living a life can say when it is complete in this sense, and its length for different individuals might range from 18 to 120 years.

The other version of a fair innings is that owing to overpopulation space on earth has to be rationed and after a time one should make way for someone else to enjoy life. (We could, of course, solve the underlying problem by controlling birth rates rather than limiting lifespan, but let us follow the logical trail.) This form of the fair innings is identified with a fixed number of years, usually assigned by Western authors to the high 70s. The assumption is that life confers some kind of intrinsic good that we can perhaps code as "happiness."

In its simplest form the argument requires that everyone has the same chance of happiness so that the fairness of the innings can be assessed by its length. Clearly this is not true. If the fairness of the innings is actually the area under a happiness/duration curve, the notion should lead to the early turning off of the rich and fortunate in favour of the poor and deprived. It would be theoretically possible to calculate an individual's fair innings allowance on the basis of some form of "happy life expectancy" adjusted for relevant variables such as social class and sex. Whether one should regard this as a serious possibility or an intellectually charming *reductio ad absurdum* depends on one's estimate of its potential utility. Given their longer life expectancy, women would probably have to

take second place to men in access to health care. Rich older people would still, presumably, be able to purchase, in the private sector or abroad, treatments denied to them by the NHS. The fair innings concept is unlikely to provide an acceptable solution to problems of inequity.

Conclusion

Health care resources in Britain are limited, but only because the government limits them. If we continue with the healthcare budget restricted to some 7% of gross national product rationing is likely also to continue. In a democratic society rationing should be explicit and transparently the responsibility of government. For several reasons it would be timely for Britain to define what its national values and the rights and duties of its citizens are. I should be disturbed if these turned out to differ essentially from those deduced above. If these values are to be translated into the NHS primary rationing has to focus on equitable limits to the type and volume of services. We should not create, on the basis of age or any other characteristic over which individuals have no control, classes of *Untermenschen* whose lives and well being are deemed not worth spending money on.

TWO PATIENTS WHO CHANGED MY PRACTICE

Mothers always know best

I inherited David and Meena when I took over medical responsibility for the special school. David's mother was 17 and unmarried when he was born 14 years ago; he had severe spastic quadriplegia and mental handicap. There were frequent messages from health professionals and school staff expressing concern about his feeding difficulties and weight gain; his weight was well below the third centile.

I always gently tried to encourage David's mum to feed him more, with exhortations about the benefits of building up his weight. Apparently I was not the only one. Finally, his mother had had enough. She firmly but assertively told me that whenever she met people from health or education they always talked about David's weight.

Did we think that she intentionally withheld his food? She pointed out that we saw him for 30 minutes but she had looked after him virtually every day for 14 years. "I'm doing my best, and if you [sic] can do any better you do it."

She was right, of course. David was always clean and well presented. He was always excited—even I could tell that—when he saw his mum at school medicals; he loved his mum and she loved him. In my next letter to her I congratulated her on being assertive enough to express her frustrations. I said that we would stop any further weighing or mention of feeding and see how David progressed. My relationship with his mother improved. And David? He remained small and happy.

Meena was also 14 and had had no net weight gain for four years. She was severely mentally and physically handicapped. She was so far below the third centile that trying to plot her weight was meaningless. Most of what she was fed in school seemed to trickle out at the corners of her mouth.

I again came under a lot of pressure to do something; there was even talk about child protection proceedings. The parents went back to Asia leaving Meena in the care

of her older sister and aunt which made discussions about feeding issues and a possible gastrostomy more difficult. We compromised by admitting her to the children's ward to assess her nutritional intake.

This was an unmitigated disaster. Meena took very little food from strangers. The nursing staff could not afford to spend hours a day trying to feed her orally. When her relatives visited her mood improved and she took some food from them. After Meena was discharged her relatives did not attend school for medicals; my relationship with the family was set back, if not irreparably damaged.

Children with spastic quadriplegia often have severe feeding difficulties. Their parents may spend several hours a day trying to feed them; they do not need to be told, however well intentioned, to feed their children more. Feeding may represent one of the few tangible and obviously nurturing parental tasks that they can do for their profoundly handicapped children.

We were guilty of setting impossible goals. I had allowed myself to be influenced by pressure from others, who I suspect were in turn influenced by the weight charts, something I would have had no difficulty resisting in "normal" children. I now take a much more informal but no less concerned approach to the nutrition of children with severe handicap, based on whether the child is content and the parents' opinions about their child's feeding. I look at the children's weight charts as a last resort.

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We welcome filler articles of up to 600 words on topics such as *A memorable patient*, *A paper that changed my practice*, *My most unfortunate mistake*, or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk.