18 Community Child Health Services*

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1 Summary

Statement of the problem

Community child health services (CCHS) incorporate a range of disparate and evolving services provided by paediatricians, community nurses, mental health professionals and physiotherapists, speech and occupational therapists, in close liaison with public health and information management staff. The staff involved in provision of these services may be managed separately from one another. The aims of the CCHS are the prevention of disease and disability and the promotion of health. Over the last decade the balance of activity between disease prevention and health promotion has changed in favour of the latter, with a greater emphasis on public health approaches. The disparate nature of these services, their divided management, their separation from other paediatric services and their low academic profile have resulted in a lack of data about performance and effectiveness which has resulted in great variation in quality of and access to care for children according to where they live.

Sub-categories: the core business

The tasks carried out within the CCHS include aspects of both primary and secondary care as well as health promotion. They include management of and advice regarding child protection, adoption and fostering, and 'children looked after' (CLA), school health services, provision of child health surveillance (CHS) (provided in most areas by primary health care teams but by CCHS where GPs are unable or unwilling to offer this), planning and monitoring of CHS, health promotion programmes, child public health, services for disabled children and those with hearing impairment (paediatric audiology), and child and adolescent mental health services (CAMHS). This chapter addresses those services, designated tiers 1 and 2, which deal with the more common, less severe problems and with health promotion and disease prevention. These services may not be a formal part of the specialist child and adolescent psychiatry services.

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* Several changes in community child health services have occurred since the preparation of this chapter during 2000–2001, and many new materials have been published. The reader is referred to the addendum on p. 630.

Prevalence and incidence

The number of children on the Child Protection Register varies from 100 to 740 per 100 000 total population. There are around 5000 adoptions per year and 53 000 children are 'looked after'. Between 1% and 3% of children have a Statement of Special Educational Need, which needs CCHS input. Up to 20% of children have educational difficulties at some time, and some but not all of these will need paediatric assessment. All children have a right to a basic programme of CHS, health promotion and school health.

There are 189 000 severely disabled children in the UK and 1.8% attend special schools. They make up 28% of children looked after.

The point prevalence of problematic psychological conditions in childhood and adolescence is around 20%, of whom half may need specialist assessment and half may benefit from professional help of lesser intensity.

Services available and their costs

The following duties of CCHS are statutory or set out in Department of Health (DoH) guidance: provision of designated doctor and nurse for child protection with input to the Area Child Protection Committee (ACPC); provision of medical advice for adoption panels; medical examinations of children taken into care (though these may be done by primary care staff in some areas); school health service including liaison regarding Special Educational Need procedures; role of immunisation co-ordinator; support for social services with regard to children in need; monitoring of PKU and hypothyroidism screening. A clear definition of medical duties regarding CLA is awaited.

CCHS provide medical, nursing and often other professional staff to manage the services set out above. A national programme of screening in child health has been put forward. Care of disabled children is usually based in a Child Development Centre or focused on a Child Development Team; this may be in a hospital or in a community setting.

Health promotion programmes in the pre-school period centre around support and advice for parents with the aim of improving the level of parenting in the population. For school-age children the most popular approach is now the health-promoting school. The role paediatricians and community nurses play in child health advocacy at local and national level varies greatly from one place to another.

CAMHS are organised in four tiers. Tier 1 is primary care, tier 2 is solo professional practice, tier 3 is specialist teams of child psychiatrists, mental health nurses, psychologists, etc., and tier 4 is highly specialised provision such as inpatient care or management of rare problems.

Costs are difficult to establish because of the wide and unacceptable variability between districts, in all aspects of CCHS and CAMHS.

Effectiveness

Many aspects of modern CCHS have a robust evidence base and others are a response to intolerable situations such as child abuse, or support legislative requirements. Many screening procedures have been discarded in recent years. Those that remain largely fulfil classic screening criteria. Immunisation and co-ordination of the service are highly effective. Health visitors and school health services are changing their practice in the light of accumulating evidence about what consumers want and what works. For disabled children, the aims are based on consumer views and quality-of-life issues rather than expectation of cure or dramatic neurological recovery. There is good evidence that high-quality services are linked with parent satisfaction. In the field of child mental health there is evidence of effectiveness of focused approaches to specific issues and of programmes aimed at parents to prevent or intervene with behavioural problems or parent depression, and to promote mental health.

Quantified models of care

There are insufficient data on the level of CCHS or CAMHS tiers 1 and 2 staffing needed. There are wide variations in the workload regarding child protection, CLA and school health work, due to socio-economic and policy differences, but variations in current staffing levels cannot be explained by these factors. Estimates have been made of time needed to discharge the duties set out in statute but not for the delivery of a quality service. For disabled children, staffing levels have been established on the basis of what is available in a sample of quality services.

Outcomes

For many CCHS activities, especially those required by statute, long-term outcome measures are of academic but not practical value, and process measures must be used as a proxy. Social, emotional and educational outcomes might in many cases offer better measures of the success of both disease prevention and health promotion programmes than measures of physical health. For disabled children, data on the process of early identification and support and parental satisfaction may be the best available measures. For CAMHS, measures for individual cases are available though not yet optimal, but population-wide measures are more elusive and depend in part on the declared stated aims for CAMHS tiers 1 and 2 of the local community and the State.

Targets

These are best defined at present in terms of coverage for all population-wide activities, and quality-of-service proxy measures for child protection, educational support, CLA, disability and CAMHS tiers 1 and 2.

Information

There is an urgent need for better information systems. A core public health data set has been devised but has yet to be included in Government policy or funded. Definition of impairments and disorders is difficult both in disability and in mental health problems, especially at the tiers 1 and 2 end of the spectrum of severity. Existing systems are outdated but could form the basis for a revised IT protocol.

Research

Research is needed on service delivery issues such as optimal staffing levels and configuration, on the impact and value of various ways of preventing and managing suspected or actual child abuse, on the benefits to be expected from better paediatric care for CLA, on new screening opportunities (especially in biochemical screening), on measures of process and outcome for disabled children and those with mental health problems, and on optimum methods of health promotion both with parents and in schools.

2 Statement of the problem

Scope

This chapter will consider community child health services (CCHS) that address the general health care needs of all children (aged 0–18 years), the health care needs of children who are vulnerable by reason of neglect, abuse or disability, and those of children who have mild or moderate psychological disorders.* Psychiatric disorders affecting young people (children and adolescents) are dealt with elsewhere in this series.[1]

Although any severe illness can be disabling, in terms of service provision the term disability will refer to conditions of the nervous system, special senses and locomotor system. Mild and moderate psychological disorders will refer to psychological problems which are less severe than psychiatric disorders but nevertheless are a source of considerable misery to children and their families.[2] Mild and moderate psychological disorders are indicated by persisting behaviour problems, distressed emotions, relationship difficulties and selective maturational delays which are, in type, common or normal in children at some stage of development. They become abnormal by virtue of their frequency, severity or inappropriateness for a particular child's age and situation compared to the majority of ordinary children. They are therefore more than the annoying behaviours displayed by most children at some time. Examples include persistent aggression towards peers, sleep problems, major tantrums, provocative behaviour towards parents, unhappy clinging or enuresis.

Child health

The general physical health of children has improved greatly over the last 100 years. However, social inequalities continue to play a major role in children's health and are related to emotional, behavioural and social problems, together with child abuse and neglect, which are now the most important causes of ill-health in childhood.[3] Worryingly, these are thought to be an important precursor to unhealthy lifestyles,[4] mental illness[5–7] and perhaps physical ill-health in adulthood.[8,9] Mild and moderate psychological problems are also a significant and widespread community child health problem. The emotional, behavioural, developmental and relationship problems included under this heading are a common source of family distress, clinically significant and represent a health care need.

Community child health services

The Children Act 1989, the Education Acts of 1981, 1987 and 1997, and the White Papers *Saving Lives* and *Making a Difference* (1999) define some of the aims and tasks carried out by the CCHS. The traditional core business of the CCHS includes primary, secondary and tertiary prevention of disease, disability and death in childhood, and the promotion of health.[10] Clinical services include the assessment and ongoing care of children with a range of disabilities (mainly but not exclusively affecting the nervous system), investigation and management of suspected child abuse, and responding to a range of other clinical concerns in clinics, schools and childcare facilities. Over the last decade the balance of activity between disease prevention and

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* Also *see* Royal College of Paediatrics and Child Health (RCPCH). *The Next Ten Years*. London: RCPCH, 2002 and Royal College of Paediatrics and Child Health. *Strengthening the Care of Children in the Community*. London: RCPCH, 2002.

health promotion has changed in favour of the latter. The aims of the CCHS may vary from one district to another due to variations in provision by other agencies and the level of social deprivation within that district.

Professions involved in CCHS

The CCHS had their origins in health visiting, infant welfare clinics and school health services (SHS) and were originally staffed by doctors and nurses employed by local authorities. When these services were absorbed into the NHS in the reorganisation of 1974, Specialists in Community Medicine (child health) in the Area Health Authorities ran them. Following further NHS reorganisations in the 1980s, CCHS are now managed by consultant community paediatricians and nurse managers, with a variable input from public health consultants. Service provision is primarily by paediatricians, community nurses, mental health professionals and physiotherapists, speech and occupational therapists.

Over the past decade, child health screening, surveillance and immunisation, which were previously delivered by CCHS, have become subsumed into primary care. Health visitors, school nurses and dedicated health promotion staff usually provide clinical health promotion programmes. There is a rapidly changing balance between the disease prevention and health promotion roles of the CCHS. Some responsibility for an overview and for the non-clinical components ('child public health') remains with public health departments, although arrangements do vary.

This chapter does not attempt to review the rapidly changing relationship between the CCHS and 'acute' or 'general' paediatric care. The boundary between acute and community paediatrics is increasingly irrelevant and management arrangements are in a state of flux. Services such as day-assessment units,[11] short-stay observation wards and 'ambulatory' care are emerging as alternatives to hospital admission.[12] There are compelling arguments for a more integrated approach to paediatrics and child health. Children with disabilities or who have been abused often need hospital care. Specialist outreach nurses and community paediatric nurses support children with complex problems, such as cystic fibrosis, at home and in school. However, the services offered by CCHS staff are often less well understood than mainstream medical and surgical paediatrics, and this is the justification for the current overview.

CCHS and children with disabilities

Although both quality of care and availability of expertise for children with disabilities have improved substantially over the past 20 years, this is still to some extent a Cinderella service. There are wide variations in provision, in the level of training, knowledge and skill among staff, and in professional attitudes to families with disabled children.[13,14] There are often tensions between health service providers, education and social services and voluntary groups in assigning responsibility for aspects of care, exacerbated by poor communication between them. Commissioning and management of services for disabled children are often weak and information is scanty. The lack of progress in implementation of the 1989 Children Act requirements in respect of children with disabilities is cause for concern.

The CCHS and children with mild and moderate psychological pathology

The category of mild and moderate psychological pathology replaces the term 'mild psychological pathology' used in the first edition of this chapter. It is not the same as psychiatric disorder and is often dealt with by staff who are not specialist mental health professionals. It affects approximately 10% of the child and adolescent population and its manifestations are characteristically polymorphous and persistent. Establishing local mental health needs in this area would ordinarily be a priority, but is difficult because there is no consensus about method, although various strategies exist. There is quite good general epidemiological information about rates of mild and moderate psychological disorders in children. However, poor co-ordination between service providers and agencies is a major problem. The tiered-service approach is endorsed as a means of tackling this. Most mild and moderate psychological pathology will be dealt with by tiers 1 and 2. There is growing experience of the new concept of child mental health worker but no randomised evaluation of their effectiveness. Both general and focused interventions are available, though there is little information on effectiveness. Most interventions are psychological rather than physical, and it is worth considering health visiting and parent training as the basis for general interventions.[15]

CCHS and health promotion

The importance of promoting mental and emotional health relative to disease prevention is increasing,[16] but the resources devoted to this depend on the model adopted. Disease prevention follows a medical model of health in which services are delivered to individuals who have or are at risk of certain diseases. Health promotion follows a holistic model, encompassing mental and social as well as physical well-being. This stresses adverse environmental and psychosocial conditions and targets policy makers, parents, teachers, pre-school teachers and others who control the environment in which children grow up.[17] Over the last decade the balance of activity between disease prevention and health promotion has changed in favour of the latter.

The evidence base for CCHS

Evidence-based practice is important in CCHS, but the disparate nature of these services, their divided management and low academic profile have resulted in a lack of data on performance and effectiveness. Some services are provided because health authorities (now primary care trusts) are charged with legal duties; these in turn reflect political pressures and expert consensus, usually enshrined in legislation.

The functions of CCHS are intertwined with those of education and social services departments and the voluntary sector (*see* Appendix 1), and it may be impossible to disentangle the effectiveness of the CCHS from that of their partners.

Current difficulties in evaluating the effectiveness of CCHS include:

- recent wide-ranging changes in their role and function
- the changing interface between CCHS, public health medicine and primary care
- an increasing emphasis on health promotion, and particularly mental health promotion, in collaboration with other agencies
- recognition of the exceptional methodological difficulties in measuring effectiveness.

The lack of data on effectiveness and performance has resulted in great variation in quality of and access to care for children according to where they live.

3 Sub-categories

Sub-categorising CCHS

Community child health services are not neatly sub-categorised. The tasks carried out within the CCHS include aspects of both primary and secondary care as well as health promotion. In the following list of sub-categories, sub-categories (a) and (b) are core business defined in part by national legislation and central guidance. Sub-categories (f) and (g) are both major clinical services provided by the CCHS and can themselves be further sub-categorised. Sub-categories (c) to (e) are less well defined, and in the framework adopted below the somewhat artificial nature of the exercise needs to be recognised.

(a) Children who have been abused, or are to be adopted or 'looked after', are the primary responsibility of the social services departments of local authorities, but need health services input from the CCHS for assessment, management and service planning.
(b) All school-age children are entitled to a school health service and there is a requirement for the CCHS to provide support and advice to Local Education Authorities.
(c) All children are included in neonatal and pre-school childhood screening, immunisation and health education programmes. The provision of this service is now mainly through primary health care teams, but much of the organisation and training are currently provided by CCHS.
(d) All children should be included in health promotion programmes and preventive services provided by the CCHS which, by working with parents and teachers, aim to change the micro-environment in which children are raised.
(e) All children benefit from activities best described as child public health – CCHS activities which influence the macro-environment in which children are raised.
(f) Services for children with a disability.
(g) Services for children with a clinically defined mild or moderate psychological problem.

Sub-categorising services provided for children with a disability

Historically this category has evolved because children with disabilities relating to the nervous system, special senses and locomotor system have a number of service needs in common. Services for children with a disability can be further sub-categorised:

(a) by medical/diagnostic category
(b) by a conceptual framework set out by the World Health Organization (WHO)
(c) by prevalence – uncommon and severe conditions vs. common, less severe conditions and problems.

In this chapter the third approach will be used.

Medical/diagnostic category

Disability in childhood is often regarded as synonymous with neurodisability, i.e. disability related to disorders of the nervous system, including the special senses (these are listed in Tables 1 and 2). Many other chronic disorders cause disability and give rise to often unmet service needs, e.g. osteogenesis imperfecta, Morquio's disease, Marfan's syndrome, neurofibromatosis and chronic juvenile arthritis. The needs of children with chronic, common, non-neurological conditions such as diabetes, cystic fibrosis or asthma are generally catered for effectively by the appropriate specialist services.

Table 1: High-severity, low-prevalence conditions.

Condition	**Incidence**	**Comments**
Cerebral palsies	2.5/1,000	Many different types and aetiologies
Spina bifida + hydrocephalus; hydrocephalus alone	0.5–2.0/1,000	Incidence varies with geographic area, socio-economic conditions and screening policy
Muscular dystrophy	1/3,000 boys	The commonest muscle disease
Severe learning difficulties or disabilities (mental handicap)	3.7/1,000	Previously called 'mental retardation' or 'educationally subnormal – severe'. Many causes – Down's syndrome, other chromosomal defects, brain injury, dysmorphic syndromes, fetal insults (alcohol, rubella, etc.). Little social class gradient with severe learning disabilities (contrast mild/moderate, *see* below)
Sensorineural hearing impairment	1.3/1,000	Multiple causes: 1.1/1,000 are congenital – genetic, congenital infections, syndrome-related; remainder acquired, commonly post-meningitis
Severe vision defects (blind or partially sighted)	1–1.5/1,000	Includes many children who are multiply handicapped. Those for whom impaired vision is the only or main problem amount to perhaps one-half or one-third
Autism and autism spectrum disorders (ASD)	0.4–2.5/1,000	The higher figure includes children with mild autistic features and those in whom autistic behaviour is part of a pattern of severe learning difficulties; the lower figure refers to 'classic' autism. Asperger's syndrome is not included – 5/1,000
Other communication disorders (dysphasia, dysarthria, dyspraxia, severe language impairments – cause unknown)	Not well established: 2–5/1,000	Difficulty in definition, therefore incidence is not certain
Epilepsy	6–12/1,000	The epilepsy is inactive at any one time in about half. It is disabling or intractable in a small minority
Miscellaneous disabling conditions		Includes osteogenesis imperfecta (brittle bone disease), achondroplasia and other dwarfing conditions, limb defects, effects of trauma (head injury, anoxic brain injury, spinal cord injury), many others

Table 2: Low-severity, high-prevalence conditions.

Condition	Incidence	Comments
Delayed language development	3–10%	Figure depends on definition and on socio-economic status
General delay: mild or moderate learning disabilities	3–10%	Same applies. Previously called 'educationally subnormal – mild'
'Clumsiness' – developmental co-ordination disorder, developmental dyspraxia	3–7%	Same applies. Link with socio-economic status is less direct but clumsiness is more common in children of lower IQ
Glue ear (secretory otitis media [SOM], otitis with effusion)	8–11%: 2–4% have severe or persistent SOM	At least half of all children have at least one episode of SOM, but severe persistent SOM is potentially disabling and impairs language development. Possible links with lower socio-economic status, passive smoking, day care and other predisposing factors, e.g. Down's syndrome
Eye defects: squint, refractive error, amblyopia	5–10%	Prevalence of squint is 4–7%. Higher figure depends on complete ascertainment of subtle cases. Incidence of short sight (myopia) rises throughout childhood and adolescence. Little social class gradient except in use of services
School failure	20%	Up to 20% of children will have problems with education at some point. The differential diagnosis includes general learning disability (low IQ), specific learning disability (e.g. dyslexia), psychological disturbances, psychiatric illness, attention deficit hyperactivity disorder, abuse, bullying, bad teaching, home problems

Conceptual frameworks for classifying disability

There is no completely satisfactory classification of disabilities in childhood for the following reasons.

- Classification must not only describe what the child can and cannot do, but also relate this to the age of the child.
- Multiple disabilities interact, e.g. a minor hearing loss may cause major problems when combined with a mild learning disability.
- The attitude of the child, parents and teachers affects the perceived extent of handicap.

In 1980, the World Health Organization proposed a classification as part of the *International Classification of Diseases* (*see* Box 1). The new version is shown in Box 2.[18] The OPCS developed a system for a national survey,[19] and the British Association for Community Child Health classification is useful for special needs.[20] Several other methods have been used.[21] Other systems such as Read codes do not currently offer a satisfactory solution to the problem.

Box 1: Definitions of terms previously used in disability research.

Impairment	An abnormality of anatomical structure or physiological or psychological function.
Disability	The function effect or deficit caused by the impairment.
Handicap	The impact of the impairment or disability on the fulfilment of the person's desired or expected social role in society. Often caused by factors external to the person, e.g. access to buildings being unsuitable for wheelchairs, but in common usage is interpreted as a negative characteristic of the individual.
Disadvantage	Has a similar meaning to handicap but is less pejorative and emphasises how disability interacts with environmental factors and societal attitudes.

Box 2: Definitions of terms: new terminology proposed in ICIDH-2.

- The concept of impairment remains. **Impairment** is a loss or abnormality of body structure or of a physiological or psychological function.
- The concept of disability has been replaced by measures of activities. An **activity** is the nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality.
- The concept of handicap has been replaced by measures of participation. **Participation** is the nature and extent of the person's involvement in life situations in relation to impairments, activities, health conditions and contextual factors. Participation may be restricted in nature, duration and quality.
- The term 'disability' has been dropped, while the term 'disablement' has been adopted as an umbrella over the concepts above.

Prevalence and incidence

It is convenient, though somewhat artificial, to divide disabling conditions of childhood into the following categories.

1 **High-severity, low-prevalence conditions:** Examples of these include sensorineural hearing loss, partial sight and blindness, cerebral palsy, spina bifida and Down's syndrome (*see* Table 1). These are:
  - individually uncommon
  - usually associated with identified or assumed pathology
  - likely to lead to disability
  - unlikely to resolve spontaneously or with treatment
  - often managed in a special centre by a multi-disciplinary team
  - likely to need services for the whole of the child's life.

2 **Low-severity, high-prevalence conditions:** Examples include speech and language impairments, mild learning disabilities and 'clumsiness'. Mild hearing loss (usually conductive in nature and caused by otitis media with effusion) and minor vision defects such as squint or amblyopia could also be included (*see* Table 2). Impaired learning and behaviour associated with attention deficit hyperactivity disorder (ADHD) may also be included in this list. ADHD is often managed within paediatric services rather than by mental health teams, either because of the potential volume of cases or because some child psychiatry services have been reluctant to take on this area of work. Low-severity, high-prevalence conditions:
  - are common

- are often either developmental (i.e. they improve with maturation, with or without intervention) or reversible by treatment
- sometimes represent the extremes of a distribution of a particular skill rather than a pathological deficiency
- are usually managed in a community setting by one or two individuals
- are unlikely to need services for the whole of the child's life.

Although high-severity, low-prevalence conditions are usually associated with substantial disability, this is not invariable. For example, some children with mild cerebral palsy walk well. Conversely, some children with low-severity, high-prevalence conditions may be quite disabled. For example, although the disability associated with the 'clumsy child syndrome' is for most children a minor inconvenience, for a minority it can cause considerable disability and unhappiness.

The two categories of disabling condition set out above are usually associated with different service needs. Guiding principles are listed in Appendix 3. Those with high-severity, low-prevalence conditions often have multiple and complex problems, and their treatment programme may involve many medical, therapy and educational specialties, often in a special school or in a unit of a mainstream school. Their families have well-defined needs[22] which were confirmed in a parent survey and summarised in the form of a 'Charter' (*see* Appendix 2).

Those with low-severity, high-prevalence conditions are more likely to be assessed in a community setting. Some, but not all, need a paediatric assessment (e.g. many children with delayed language development are seen only by a speech therapist and an audiologist), and they are likely to attend mainstream school.

Mild and moderate psychological disorders

When planning services for children with mild or moderate psychological disorders, it is appropriate to sub-categorise further by age and by number of problems in any particular child or adolescent, because these will influence the type of service delivery.

Age

It is relevant to differentiate between three main age groups, since the way in which children and teenagers come to the attention of services differs between them:

- pre-school children, who will be presented to health services by their parents
- school children, who may be presented either by their parents or by education staff
- older adolescents, who may present themselves.

Number of problems

This needs to be considered because of the type of clinic which is best placed to cope.

- Single problems, such as sleep difficulties or enuresis, may be addressed by special clinics or services.
- Several coexisting behaviour, mood or relationship problems in any one child or teenager will need a more flexible approach, tailored to the individual child and family, and to the priorities within a range of problems, so that a general clinic or service is therefore more relevant.

4 Prevalence and incidence

Children who are the primary responsibility of social services departments

Data are published each year on the numbers of children on Child Protection Registers, the categories of registration, the numbers of children put forward for adoption, and the numbers of children looked after by local authorities, including those in residential care and those looked after by foster parents.

Child abuse is not a well-defined clinical entity, and the level of abuse meriting intervention varies depending on prevailing social attitudes. An increasing number of health problems, including emotional and behaviour problems in childhood,[23] health-related lifestyles,[24] and physical and mental health in adulthood[25] appear to be attributable in part to common ‘parenting styles’ which are unhelpful to children’s health and well-being but are not defined as abusive. The number of children on the Child Protection Register in the year ending March 1997 ranged from 100 to 740 per 100 000 total population. This wide range reflects real differences in the incidence of child abuse, differences in levels of ascertainment, variation in the services which facilitate the management of at-risk children without the need for registration, and the differing policies and attitudes of local authorities.

The number of adoptions reached a peak in the early 1970s and has since declined to a current level of around 5000 per year, but many adoptions are now of children with disabilities or complex emotional needs. The number of ‘looked after’ children is estimated to be around 53 000, but at local level varies by a factor of ten across the country.

School-age children: support and advice to the Local Education Authority

All school-age children are entitled to a school health service. The CCHS also provides support and advice to Local Education Authorities (LEAs). One such area is in the issuing of Statements of Special Educational Need (SSENs) (*see* Box 3 and Appendix 4). The number of children with SSENs varies widely between education authorities, from under 1% to over 3%. There is some correlation with deprivation levels and the proportion of children with SSENs, but the variation also reflects differing policies and interpretations of official guidance. Up to 20% of pupils may have special educational needs at some time, but only a minority of these progresses to stage 5 of the assessment process, which results in the issuing of a Statement of Special Educational Need. Most authorities are trying to reduce the number of children with Statements of Special Educational Need and deal with problems at levels 2 and 3 of the assessment process.

Box 3: Statements of Special Educational Need.

- A Statement of Special Educational Need is a legal document prepared by the Local Education Authority under the Education Acts of 1981, 1993 and 1996, and the Education Reform Act of 1988. It defines the child’s needs and the provision to be made in order to meet those needs.
- The Code of Practice 1994 set out the details of how the process works; it has recently been revised.
- Preliminary steps are set out whereby efforts are made to resolve the child’s difficulties without a formal Statement of Special Educational Need procedure.
- The health authority (now PCTs) is required to provide the necessary medical evidence regarding the child’s needs.
- There must be a doctor designated to take responsibility for ensuring that the procedures and time limits are complied with.

All schools operate some process of identification of children with possible health problems or special needs at school entry, and identified children are usually referred for a medical assessment ('selective school entry medicals') (*see* 'School medical inspections' in Section 5). In published studies the number of children selected varies from 17% to 73% of the population.[26] Some of these may be seen more than once. The number of vision, hearing and growth problems identified at school entry is reviewed under disabilities.

Organisation of screening, immunisation and health education programmes

The aim of these programmes is to reach all children. The performance of screening programmes and the potential contribution of health education are discussed in *Health For All Children.*[27]

Organisation and provision of health promotion services and preventive services which focus on the micro-environment and child public health: services which influence the macro-environment

The main health problems which these programmes aim to prevent are summarised in Table 3. Important issues which will in general be aimed at parents, with the child being the benefactor, in the pre-school period include injuries[28] (accidental and non-accidental), sudden unexpected death in infancy, speech and language delay, emotional and behavioural problems, passive smoking and lack of breastfeeding. The latter

Table 3: Common health problems which the CCHS aims to prevent.

Deaths per annum	
Sudden unexpected death (0–1 years)	1.0/1,000
Unintentional injury (0–19 years)[30]	8.6/100,000
Suicide (15–19 years)	3.5/100,000
Child abuse (0–1 year)	1.4/100,000
Incidence of common health problems per annum	
Injury requiring attention at A&E (0–15 years)	200/1,000
Disabling injury (16–23 years)[31]	4.0/1,000
Pregnancy (16-year-old girls)[32]	20/1,000
Prevalence of common health problems and unhealthy lifestyles	
Emotional and behavioural problems (5–10 years)	5–20%
Speech and language delay	5–10%
Depressive symptoms (adolescent girls)	20%
Major depressive disorder (adolescent girls)	10%
Exposed to passive smoke at home (0–16 years)	50%
Not breastfed at six weeks	61%
Not breastfed at six months	79%
Sexually active at 16 years[33]	50%
Regular smoker before leaving school	25%
Drinking alcohol above limit (16–17 years)	5%

two, together with sound weaning practices, are important with respect to respiratory and gastrointestinal infection, glue ear and dental disease, which are common causes of consultation with doctors and dentists, and of hospital admission in the pre-school age group.

In the school years the focus of these programmes is on the children themselves and concentrates on promotion of mental health and healthy lifestyles, and the prevention of injuries, substance misuse, teenage pregnancy, sexually transmitted diseases and mental health problems in adult life.[29] Most common child health problems, particularly injuries, demonstrate social inequalities. A range of intertwined psychosocial and environmental factors, including poverty, unemployment, teenage parenting, single parenting, poor housing, inner-city neighbourhoods and parental criminality, increase the risk of all these problems.

Children with disabilities

There are 360 000 disabled children in the UK (32 per 1000 or 3% of the child population). Of these, 189 000 have severe disabilities, and of *these*, 5500 live in residential care and 16 000 attend residential schools. In total, 1.8% of all children attend special schools.[19] Disabled children are eight times more likely than non-disabled to be looked after by the local authority, and constitute 28% of all children looked after.[34] There are increasing numbers of children with disability who attend mainstream schools, and many need considerable support. There are many more children, estimated at 20% of the school population, who have special needs during their school career, and some though not all of these need paediatric services. Secondary problems are common among all such children, e.g. behavioural and emotional difficulties, family stress and disturbances, concomitant medical problems, bullying and loneliness. Tables 1 and 2 above summarise prevalence and incidence data for the more important disabling disorders.

Mild and moderate psychological disorders

Raw data from a number of epidemiological studies in childhood yield a point prevalence rate of approximately 20% for problematic psychological conditions in childhood and adolescence.[35] About half of these would be regarded as sufficiently severe for specialist assessment by a psychiatric service. The criterion for inclusion within this group is the presence of 'considerable distress and substantial interference with personal function' as well as the fact that the condition can be classified within the *International Classification of Diseases* (10th edition). (*Note*: These are the criteria used in the Office for National Statistics Survey to delineate 'mental disorder'[36] which is equivalent to the term 'psychiatric disorder'.) The remaining 10% are less impaired or not readily diagnosable in ICD-10 terms. This group normally has emotional, behavioural, relationship or psychological abnormalities which are clinically significant (by virtue of mild/moderate distress or impairment), and which are able to benefit from health care, but which are not sufficiently severe, pervasive, distressing or handicapping to be regarded as psychiatric disorders. This is the field of mild and moderate psychopathology. It includes subjective mental distress (e.g. obsessional symptoms unaccompanied by compulsions) which is complained of by the child or adolescent but which is mild/moderate because it does not intrude into the child's observed demeanour, does not affect their personal functioning and goes unnoticed by parents or teachers.

Risk factors can be identified for mild/moderate psychological pathology, and resemble those found in psychiatric disorder (*see* Box 4).

Box 4: Risk factors for mild and moderate psychopathology.

- Poor parenting practice.
- Inner cities.
- Socially disadvantaged or poor families.
- 'Looked after' children in public care.
- Being male rather than female.
- Having general and specific learning difficulties and, in young children, delayed language development.
- Having physical problems of health or development.
- Adolescence rather than earlier childhood.

If a population in which risk factors are common is sampled, figures for the prevalence of psychological problems are likely to be substantially higher since such factors tend not simply to sum, but usually multiply the impact of each other. For instance, work in inner South-East London[37] found that 68.6% of pre-school children in a random survey were judged by interviewers to have at least one psychological problem and 29.1% to have three or more problems.

Associated family relationship problems are common though not universal. They are most evident in association with multiple problems. In general terms they parallel findings for psychiatric disorder in childhood, so that there are higher rates of:

- marital discord/altercations/divorce
- mental health problems in other family members
- parental coldness or irritability towards the child
- low degree of parental supervision of the child.

For planning purposes, a number of proxies for child and adolescent mental health need have been used (*see* Box 5), and can logically be extended to suggest health need related to mild and moderate psychopathology in childhood. For most services, history has been the major factor in determining the volume of services for children with psychological pathology. Across the UK there is an extremely poor relationship between the volume of local relevant services and local need as suggested by such proxy indicators.[38]

Box 5: Proxies of need for estimating local child and adolescent mental health need.

- Perinatal mortality rate.
- Infant mortality rate.
- Under-16 pregnancy rate.
- Proportion of lone-parent families.
- Number of children in temporary housing.
- Number of children on the Child Protection Register.
- Number of children looked after by the local authority.
- Number of children with a Statement of Special Educational Need.
- Number of children on the disability register.
- Number of children accommodated with private fostering agencies.
- Number of children absent from school without authority.
- Number of children excluded from school.
- Number of young carers.
- Number of refugee children.
- Number of young people involved with the police.[7]

Rates for particular problems

Various epidemiological studies (predominantly UK-based) have yielded relatively precise point prevalence figures for some single problems, abnormal in terms of frequency, severity or age expectation. For the sake of illustration, some of these can be selected and collapsed to yield crude overall percentage figures for the general population in three age groups.[1,2,39–41]

In pre-school children (under 5 years of age)

- Waking and crying at night: 15%.
- Over-activity: 13%.
- Difficulty settling at night: 12%.
- Refusing food: 12%.

For polymorphous pre-school behavioural problems involving a combination of high activity levels, disobedience, tantrums and aggressive outbursts, associated with tearfulness and clinging, a point prevalence figure of about 10% can be estimated among 3-year-olds.

In middle childhood (age 6–12 years)

- Persistent tearful, unhappy mood: 12%.
- Bedtime behavioural rituals: 8%.
- Night terrors/other disturbances of sleep: 6%.
- Bedwetting: 5%.
- Inattentive over-activity: 5%.
- Faecal soiling: 1%.

A general rate of significant psychological problems in middle childhood is generally understood as being 12–25% (according to whether the domicile is semi-rural or urban, respectively), from which need to be subtracted those children with overt, handicapping psychiatric disorder (7–14%), yielding a prevalence rate for ‘mild’ emotional and behavioural abnormality of 5–11%. Much of this will be of a mixed, polymorphous type with various combinations of anxious unhappiness, difficult or antisocial behaviour, and poor relationships with other children.

In adolescence (age 13–18 years)

- Appreciable misery: 45%.
- Social sensitivity: 30%.
- Evident anxiety: 25%.
- Suicidal ideas: 7%.

On the basis of epidemiological data it has been estimated that about 10% of the general adolescent population suffer from more complex depressive moods (‘marked internal feelings of misery and self-depreciation’).[42] This is in addition to those diagnosed as having psychiatric disorder (including major depression, which appears to have a point prevalence rate of 2–3%).

Prevalence or incidence?

Current evidence strongly suggests that mild or moderate psychological problems are relatively persistent, particularly when linked with continuing abnormalities in family relationships. This is true even for young children. In two large studies, at least half of 3-year-olds rated as having behaviour problems were still rated as displaying problems several years later.[2,43] Studies on psychiatric disorder (interpreted widely) in adolescent populations imply a similar degree of continuity. For instance, nearly half the psychiatric disorder in 14–15-year-olds is constituted by conditions which have persisted since childhood.[9] Although some studies have used a follow-up design from which it might be possible to obtain an inception rate, the use of different instruments for different age groups and a lack of stratification of severity from one sampling period to the other makes this impossible. There is therefore no hard information on incidence within a total childhood population as far as mild and moderate psychological pathology is concerned. Sometimes a moderate disorder shows a tendency to develop into a psychiatric disorder. This is the case with the American concept of dysthymic disorder which, in clinic populations at least, shows a marked tendency to develop into major depression over a few years.[44] There are insufficient studies to establish how frequent this phenomenon is when applied to all mild and moderate psychopathology in childhood.

5 Services available

This section describes the range of services available in each of the sub-categories, most of which are provided by the same group of staff. Only a few sub-categories, e.g. school health services, are provided by dedicated staff, e.g. school nurses.

Costs of community paediatrician services are difficult to interpret because the division of labour between hospital and community trusts varies so widely. Clinical practice also varies.[45] There have been a few attempts to cost the sub-categories of the NHS independently of one another[46,47] (*see* Box 6). These are discussed throughout this section.

Box 6: Examples of attempts to cost CCHS.

The costs of 'core' CCHS have been assessed in four recent studies:[31,45,47]

- a detailed study on child protection and school health conducted in four districts
- a postal and telephone survey gathering data on school nursing and health visiting from 62 districts
- a resource allocation study on health-visiting activity in one city
- a questionnaire and observational study of child health surveillance.

In the first two studies, costs were referred to a notional primary care group (PCG) (now superseded by primary care trusts (PCTs)) population of 100 000, with 20 000 pre-school and school-age children. Figures were based on 1996 pay scales and were estimated or likely costs rather than actual costs as many community child health staff remain in post for a long time and are at or near the top of the salary scale. Employers' costs were added, but no overheads or capital costs. Costs were rounded to the nearest £1000, or to the nearest £10 000 where larger sums were concerned (*see* Figure 1). The term 'district' is used for convenience and a population of 1 million, or 10 PCGs, is assumed. 'Health visitors' (HVs) or 'school nurses' (SNs) are shorthand for any staff paid from these budgets.

The costs of disability care have not been studied in detail.

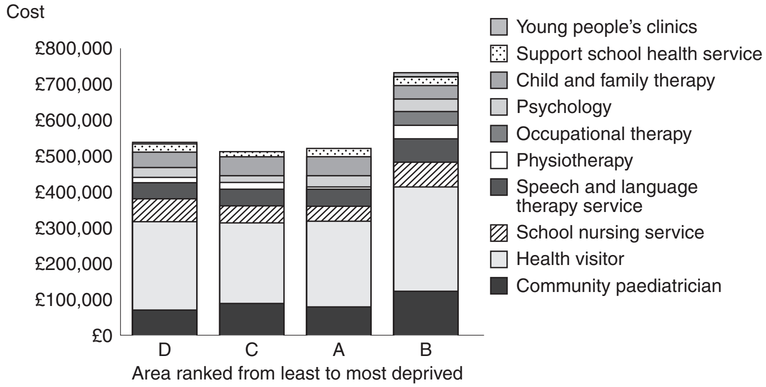

Figure 1: Comparative cost of core CCHS per 10 000 children aged 0–14 years, based on a detailed study in four districts.

Health service support for children who are the primary responsibility of social services departments

Key components include the early identification, prevention and management of child abuse,[48] adoption and fostering, and 'looked after' children (*see* 'Children who have been abused or are at risk of abuse', 'Adoption' and '"Looked after" children' below, respectively). There is a statutory obligation for CCHS to provide medical support to the social services departments of local authorities. Section 27 of the Children Act 1989 required health authorities (now PCTs) 'to comply with requests for help from local authorities in respect of children in need, provided the request is compatible with their statutory duties and does not unduly prejudice the discharge of any of their functions' (*see* Appendix 5). Social services may seek medical support for children whether they are at home, at school or in hospital. The statutory duties are undertaken by designated professionals[49,50] who are 'a nurse with health visiting experience' and 'a doctor with wide experience of child protection', plus supporting staff. The doctor is usually a consultant, but this is not specified in the guidelines (*see* Appendix 4, Appendix 5 and Appendix 6). The designated doctor role includes a substantial teaching and training element.

Children who have been abused or are at risk of abuse

There are four categories:

- physical abuse
- sexual abuse
- neglect (including failure to thrive)
- emotional abuse.

Children may present with overt injuries, failure to thrive or neglect, or because of parental distress. They may be identified at home or at school, or they may disclose sexual abuse to a trusted adult or a helpline; they may also be the victim of assault by a stranger. Much abuse goes unreported and occasionally the abuse is only recognised after death. NHS staff provide expert advice to social services, who have the lead responsibility to determine whether abuse has occurred, to decide whether children's names should be placed on the Child Protection Register and to construct a child protection plan. Prevention of child abuse is one of the aims of the general health promotion programmes (*see* below).

Costs

In calculations that assume a primary care group (PCG) (now PCT) has a population of 100 000 and a district has a population of 1 million, the mean clinical child protection costs for four districts studied in detail were £52 000 (range £35 000 to £75 000). The mean contribution to the annual cost of the nursing and support component was £20 000 per PCG, but the investment would be higher than this in areas with high deprivation scores. The health service input to support and help abused children and their families was a mean of £8000 (range £4000 to £12 000). This shows that more effort is invested in identification and investigation of abuse than in prevention or treatment.[51] Provision of counselling for children who have been abused is limited by inadequate resources. Formal therapy is rarely available and treatment for the perpetrator is the exception.

Adoption

Each health authority (now PCT) CCHS is required to provide a Medical Adviser (MA) for the local authority's adoption panel (*see* Appendix 6). This task ideally requires experience in paediatrics, adult medicine, genetics and psychiatry. In recent years, there has been a decline in the number of healthy babies offered for adoption and a steady increase in the number and proportion of children offered for adoption who are either disabled, or emotionally damaged due to abuse, neglect or multiple foster placements. Parental substance abuse has become an important reason for adoption. The prospective adoptive parents may themselves have a range of health problems or unusual lifestyles.[52] Adoptive parents need the same information and advice as would be given to natural parents. At present there is little investment in post-adoption services, but psychological support and guidance would be helpful for many adopted children and their birth and adoptive parents.

'Looked after' children

Organising and monitoring medical examinations for 'looked after' children is time consuming, but the legal responsibility for arranging these assessments lies with the social services departments. The MA of the health authority (now PCT) has a major role in ensuring appropriate medical care for 'looked after' children.[53] The requirements for medical examinations address the needs of children who are looked after in foster care or in a residential unit. It is important to respond to educational, emotional and mental health needs as well as physical illness or abnormality, and to offer opportunities for giving advice to foster or adoptive parents or other caregivers. Pre-school children and those known to have special needs coming into care for the first time may have unresolved health issues, and their first health assessment is likely to require the skills of a paediatrician. The needs of older children are generally for psychological support and health education, and above all they need continuity of care. This can be provided by a paediatrician, but a primary care team with an interest in the mental health of young people might be more appropriate. There is no statutory medical responsibility for meeting the needs of children fostered privately, but these children have similar needs.[34] (Part IX of the Children Act 1989 places duties on foster and natural parents and the local council in respect of private fostering, though these regulations are often ignored.)

The approach to the needs of 'looked after' children has been updated in the programme 'Quality Protects', which aims to tackle the very poor long-term outcomes, in terms of educational achievement and adjustment to adult life, observed in a high proportion of 'looked after' young people. A more flexible approach will be introduced involving paediatricians, nurses and other professionals, as needed.

Multi-agency working

The Children Act 1989 and the 1986 Disabled Persons Act specify the importance of and the requirement for collaboration between agencies. CCHS make a major contribution on behalf of the NHS to this work, and recent Government initiatives, e.g. in respect of 'looked after' children, underline its importance.

Support and advice to the Local Education Authority: the school health service

CCHS have statutory duties with regard to education (*see* Appendix 4),[54] but the existing legislation leaves the precise nature, volume and quality of input to local interpretation, and there is a resultant wide variation between districts. The term ‘health needs of school-age children’ is generally preferred to ‘school health service’ (SHS),[55] but the term SHS is convenient and will be used in this section. The main tasks undertaken by the SHS are shown in Box 7, though some of the tasks listed are no longer considered to be an appropriate or optimal use of professional time, in particular tasks 19 and 25. It is suggested that every school should have a named school nurse, although each nurse may provide services for more than one school.

Box 7: Tasks which may be carried out by the school health service.

1 Medical examination of all school entrants (age group 4–5 years)
2 Developmental examination of all school entrants
3 Assessment of all school entrants in person by school nurse
4 Assessment of school entrants by school nurse, using questionnaire to parents to select those who should be seen in person
5 Vision test at school entry
6 Hearing test at school entry
7 Screening for scoliosis
8 Height and weight at school entry
9 Vision, hearing and height in subsequent years
10 Immunisation
11 Medical examination required in connection with the ‘Statementing’ procedure specified in the 1981 Education Act
12 Child protection: examination, advice, support, liaison
13 Handover of children with special needs to adult services: required by Education Code of Practice 1994, but important even if the child has no Statement of Special Educational Need
14 Medical, psychological and social evaluation of children referred by teachers or parents because of problems in school
15 Preparation and support of care plan for special needs children in collaboration with Special Needs Co-ordinator (SENCO)
16 Information for and about special needs children, particularly when placed in mainstream schools, and relating to children with health problems
17 Counselling and consultation service, particularly in secondary schools
18 Support to educational social work service; working with parents for children out of school, etc.
19 Dealing with head lice
20 Environmental health issues
21 Sharing policy development for, and taking part in, health promotion and education programmes
22 Advice to school headteachers regarding the health of children travelling on school journeys or participating in unusual sports
23 Providing an informal support and advice network for teachers
24 Hands-on nursing care, e.g. gastrostomies, tracheotomies, tube feeding, medications
25 First aid

School medical inspections

When the school health service was developed at the beginning of the twentieth century, its main function was to undertake periodic medical inspections. Few CCHS now undertake routine medical examinations on all children at any age, but most offer a school entry health check by the school nurse, which might result in referral to the school doctor (selective school entry medical). These checks aim to identify health issues of relevance to the school, and unmet health needs such as lack of immunisation or unrecognised asthma. Most CCHS screen children's vision, height and hearing on school entry. Children who have problems or suspected problems may be seen again for further assessment. Substantial nursing resources are devoted to these routine health assessments, which are often also used for health education of parents.[46]

Immunisation programmes

Most districts offer schoolchildren both the BCG (bacille Calmette-Guèrin) vaccine and a booster dose of polio, tetanus and diphtheria in secondary school. Many schools still offer rubella immunisation to girls at 13 years. Mass immunisation campaigns, such as that conducted for the meningococcal C vaccine programme, and intensive short-term projects to deal with outbreaks of infectious disease in schools or nurseries, often enlist the help of CCHS. This is very disruptive to routine work.

Special needs children

The revised Code of Practice 2001 sets out guidance for the assessment and care of children with special needs.[56] Most of the CCHS activity related to the identification of children with special needs is undertaken in the pre-school period (*see* 'Organisation of neonatal and pre-school childhood screening, immunisation and health education programmes' below). The SHS may identify a small number of children with acquired rather than congenital problems at school entry (*see* 'School medical inspections' above). Integration of disabled children in local mainstream schools is rightly the aim where possible. However, children with complex disorders and needs require additional health service input and support. This is more difficult to provide for a few children scattered around a large number of mainstream schools than when these children are concentrated in a few special schools. The role of the SHS with regard to special needs children is to undertake medical examination and report on children who may have special educational needs and to ensure that they have access to the appropriate health services. The SHS may help teachers to manage these children, facilitating full integration into mainstream school. The school nurse interprets medical information for the school, though this may be difficult if the condition is obscure or the documentation unclear. Children may need specialised hands-on nursing care in school to enable them to continue in mainstream schooling. This may be provided by a school nurse, usually supported by a specialist nurse, or by a community-based or hospital outreach nursing team.

Other school nurse roles

School nurses have a supportive and advisory role for children with health problems and are involved in the assessment and follow-up of children for whom there are child protection concerns. Teachers value the advice of school health staff when dealing with other sensitive issues, such as teenage pregnancy, or use of medication, such as inhalers for asthma. Some school nurses identify and work with the educational welfare officer (educational social worker) to help children who are no longer in school because of exclusion (usually because of repeated or serious breaches of school behaviour policy), truancy, chronic fatigue syndrome, illness, school phobia, pregnancy, etc. (*see Exclusions from School* [DfE Circular 10/94] and *Education by LEAs of Children Otherwise Than at School* [DfE Circular 11/94]).

Profiles

Another task in some SHS is to compile a profile of health needs using the knowledge of health and education staff. This would include the number of children with Statements of Special Educational Need, health problems and teenage pregnancies, and the profile from each general practice of children with health needs attending those schools.

Health promotion

The SHS may support school-based health education initiatives to prevent substance misuse, injuries, teenage pregnancy and sexually transmitted diseases, or to promote healthy lifestyles and mental health in schools. School nurses and occasionally doctors may take part in classroom health education sessions, particularly those involving sex education, usually working with a teacher. Many school nurses want more involvement in school health promotion programmes (*see* 'Child public health: services which aim to influence the macro-environment' below) and some have been involved in the development of health-promoting schools and school policies on smoking, bullying or sex education.

Multi-agency working

The Education Act 1993 and its accompanying Code of Practice 1994 specify the importance of and requirement for collaboration between agencies.

Organisation of neonatal and pre-school childhood screening, immunisation and health education programmes

Responsibility for both the clinical and (in some practices) organisational aspects of the programme, originally called Child Health Surveillance and now re-defined as Child Health Promotion (identification and prevention of health and developmental problems) and immunisation, has now been largely taken over by the primary care teams. A few general practitioners have opted not to provide this service and it is offered by CCHS instead. The content of the programme was agreed by a national consensus, and is published as *Health for all Children*.[27] Formal screening programmes (*see* Table 4) are kept under review by the Children's Sub-Group of the National Screening Committee, which was established in 1998 to advise on screening policy for children. The recommended immunisation schedule is published and updated by a national committee organised by the Department of Health. The Child Health Promotion programme also ensures that parents have access to important health information, such as the dangers of passive smoking, recommended sleeping position, the advantages of breastfeeding and advice on weaning, diet and injury prevention.

Community paediatricians provide consultant advice for children with suspected developmental or learning disabilities, referred as a result of the screening programmes arising from parental or professional concern, to establish whether they do or do not have developmental problems and might in future have special educational needs. As the threshold for referral is necessarily low, the number of children seen is high relative to the number of problems identified, and the workload in community paediatric clinics may be substantial.

CCHS also co-ordinate provision of the above services, ensure that they evolve to meet changing health needs, monitor performance (uptake, false-positive rates and number of cases identified) and provide continuing medical education for GPs and in-service training for nursing and other staff. The introduction of new screening programmes and disinvestment in out-of-date programmes involve negotiation and

Table 4: Inventory of child health screening programmes.

Screening programme	**Targets – aims**	**Evidence status***	**Comments**
Neonatal examination as an entity	Identify range of congenital anomalies	2	Under evaluation by working group of Colleges
Examination (clinical) for congenital dislocation of the hips (CDH)	Identify CDH	3	MRC research programme
Examination for CDH with ultrasound	Identify CDH; reduce false positives; facilitate management	4	MRC research programme
Check for heart disease in neonate	Identify congenital heart defects, especially those presenting early	2	Unresolved
Undescended testes in neonate	Identify undescended testes	2	Systematic review requested
Eyes: inspection	Identify anomalies, blindness	2	Evidence to be reviewed by CSG†
Eyes: ophthalmoscope	Identify cataracts	2	Evidence to be reviewed by CSG
Hearing screening in newborn – all babies	Identify permanent congenital hearing impairment	5	20-site pilot programme announced by Minister
Hearing screening in newborn – selected at-risk babies	Identify permanent congenital hearing impairment	1	20-site pilot programme announced by Minister
Biochemical screening: phenylketonuria/ congenital hypothyroidism	Identify PKU and CHT; prevent intellectual impairment and brain injury	1	Established, but quality management mechanism under review
Biochemical screening: cystic fibrosis	Early detection; treatment; genetic advice	5	Minister announced intention to introduce nationwide screening
Biochemical screening; Duchenne muscular dystrophy	Early detection; genetic advice	4	Research project continuing in Wales
Biochemical screening: tandem mass spectrometry	Early detection of range of conditions: medium-chain acyl CoA dehydrogenase deficiency, glutaric aciduria type 1, others	5	HTA reports have been considered; new research to be commissioned
Biotinidase screening	Detection and treatment of rare disorder causing brain damage	5	Not regarded as priority
Biochemical screening for congenital adrenal hyperplasia	Early detection and treatment	5	Not regarded as priority
Biochemical screening for neuroblastoma	Detection and treatment	6	
Screening for coeliac disease	Detection of occult cases	6	

Continued overleaf

Table 4: Continued

Screening programme	Targets – aims	Evidence status*	Comments
Screening for haemoglobinopathy	Antenatal/pre-conceptional screening to offer reproductive choice; detect sickle-cell disease in neonate and prevent infection/crisis	2/5	Screening programme for sickle-cell disease announced; implementation study under way
Screening for neonatal liver disease	Detection of biliary atresia and related disorders	4	Research to be reviewed by CSG
6–8-week examination of infant	Identify range of anomalies, management problems, feeding problems	2	
Screening for postnatal depression	Treat mother; prevent adverse effects on baby	3	Evidence under review
6–8-week check for CDH	Identify CDH missed previously	3	MRC research programme in progress
Check for undescended testes (UDTs)	Identify UDT missed at birth; reduce referrals (fewer UDTs at 8 weeks)	2	Systematic review to be commissioned
Monitor weight gain	Identify failure to thrive	3	'Coventry consensus' meeting on growth monitoring – recommendations published
Observational check on CDH at 5–8 months	Identify missed cases	2	MRC research programme
Hearing test at 6–8 months	Identify permanent and transient hearing loss	3	Will be phased out when newborn screen established
General review of health and progress: 8 months	Identify range of developmental problems	2	
Check for iron deficiency at 1–2 years	Identify and treat anaemia and iron deficiency; improve diet	4	Primary prevention more likely to be effective
Review walking at 1–2 years	Identify missed CDH	2	MRC research programme
General review: 2 years	Identify developmental and speech problems, behaviour disorders	2	Evidence supports more parent involvement and primary prevention
General review: 3½ years	Ditto, plus health check	3	To be reviewed by CSG
Check heart and pulses at 3½ years	Identify heart defects and coarctation	2	To be reviewed by CSG
Check for UDTs at 3½ years	Identify missed cases and ascending testes	2	Systematic review to be commissioned
Height monitoring from 2 years of age to puberty	Detect conditions affecting growth; provide public health data	5	'Coventry consensus' meeting on growth monitoring – recommendations published
Weight monitoring: body mass index	Detect obesity and under-nutrition; intervene where needed; public health data	5	'Coventry consensus' meeting on growth monitoring – recommendations published

Vision screening: pre-school	Identify squint, impaired vision, amblyopia	3	Systematic review published in 1997
Vision screening: school entry	Identify squint, impaired vision, amblyopia	3	Recommendation to provide orthoptic screening between 4 and 5 years
Hearing test: school entry	Identify missed permanent hearing impairment, conductive hearing loss	3	Results of research in progress awaited
School entry examination by doctor	Identify anomalies and disease	3	Systematic review completed; *see* website‡
School entry review by nurse	Identify disease; health promotion	3	*See* website
Vision screening at ages 7, 9, 11 and 14	Identify acquired vision problems, myopia	3	*See* website
Colour vision screening at age 5, 7 or 11	Identify colour vision defects; educational advice, careers planning	3	*See* website
Blood pressure screening	Identify hypertension (secondary, essential)	6	
Dental care	Reduce decayed, missing, filled rates; reduce periodontal disease	3	Evidence to be reviewed by CSG
Haemoglobinopathy: screening of teenagers pre-conception	Detect carriers	4	Little evidence as yet
Cardiomyopathy (HOCM)	Detect at early stage; avoid sudden death risk	4	Probably not justified
Autism	Detect at or before age 2; possible early intervention	4	Not recommended
Specific developmental motor co-ordination disorder (dyspraxia)	Identify 'clumsy' children; therapy programme to improve educational outcome	4	Not recommended
Specific reading disorder (dyslexia)	Identify children at risk; investment in pre-literacy skills and remedial reading	4	Initiatives in both health and education sectors
Hyperlipidaemia	Identify in order to reduce risk of ischaemic heart disease	4	Primary prevention more important except possibly for those with significant family history

* 1 = established, accepted, good evidence; 2 = established and accepted but evidence base not secure; 3 = established but being actively reassessed/challenged; 4 = not established – small-scale implementations, pilot or research studies in progress; 5 = active evaluation of new proposal; 6 = proposals not currently being evaluated or implemented.

† CSG = Children's Sub-Group of the National Screening Committee.

‡ Websites refer to: www.health-for-all-children.org for updates on the progress and contents of *Health for All Children* (4e) and the website of the Children's Sub-Group of the National Screening Committee for information about screening: www.nsc.nhs.uk/ch_screen/child_ind.htm

liaison in addition to the teaching required for the staff. These substantial tasks are undertaken by or shared between a community paediatrician in CCHS, a hospital-based general paediatrician, a consultant in public health medicine and/or a senior manager.

In some districts, CCHS administer the scheduling of immunisations and health checks on behalf of primary care teams. CCHS carry out this function for all school health programmes. The management and administration of the community child health information system, including updating, quality control, downloads and analysis, feedback and audit, are also covered by CCHS. These computer systems support the monitoring of screening programmes and health needs assessment, but their full potential has not been exploited. The role of the immunisation co-ordinator is discussed below.

Three pre-school screening programmes in which the CCHS currently have a role in most districts are commissioned and provided outside primary care. These are the neonatal biochemical programme (which aims to identify phenylketonuria, hypothyroidism and, in some districts, cystic fibrosis and haemoglobinopathies), the pre-school vision screening programme and the neonatal hearing screening programme. The first of these involves midwives and regional laboratories, but the responsibility for service quality must be defined and may rest with a member of CCHS.

Many districts provide orthoptic pre-school vision screening programmes. These are usually managed by ophthalmic services, but the call and recall function and change management may be the responsibility of CCHS. In other districts, health visitors or GPs undertake some vision screening as part of the general preventive programmes.

Many districts now provide selective or high-risk neonatal hearing screening, using oto-acoustic omissions and brainstem-evoked response audiometry. These services are organised in various ways, but generally involve a department of audiology and/or an audiological scientist. Over 40 areas of England are currently carrying out neonatal screening (*see* www.nhsp.info for details of the newborn hearing screening programme).

There are some antenatal and neonatal screening programmes in which CCHS currently play little part, such as screening for haemoglobinopathies, HIV and hepatitis B, but the need for a more co-ordinated approach may mean a greater role for CCHS in the near future.

Organisation and provision of health promotion programmes and preventive services which influence the micro-environment

This role is undergoing rapid development in response to changing health needs. Resources are beginning to be devoted to the provision of emotional and social support to parents, and the development of parental self-awareness, self-esteem and parenting skills. These holistic programmes aim to reduce child abuse, neglect, postnatal depression and behaviour problems, and increase school readiness. The NHS may provide them alone or in collaboration with other agencies, on joint finance, by way of central government grants, or on charitable donations. Health-promoting programmes are not the sole preserve of health professionals[57] and may be undertaken, for example, by social workers, community workers, trained lay visitors, as in the 'community mothers' programme', or non-government (voluntary or charitable) organisations such as Home Start.[58] All those working with 'difficult' families need an effective support and management network.

Pre-school parent support programmes

The Child Health Promotion Programme includes a basic service in the home and in clinics for all families. All parents are visited at home at least once, and open-access clinics are provided by health visitors in general practice and community clinics. Parents who face specific difficulties (psychosocial, economic, environmental or health-related) are offered intensive health visitor support at home.[59,60] This targeting or high-risk approach enables health visitors to spend time with parents in greatest need and is widely supported as a good way of using scarce resources. The extent of and criteria for targeting vary widely. Targeting may be formal (selection on defined criteria) or informal (selection on the basis of professionally defined 'need', e.g. incipient postnatal depression). Resources may be targeted so that there are more health visitors in socio-economically deprived areas. Within each case load, health visitors may spend more time on clients with priority needs. Within each family, health visitors seek to ensure that the problems addressed are those which are most important for that individual.

An alternative to one-to-one work is to provide services to parents in groups, either on a drop-in basis or in structured programmes. Structured parenting programmes[61,62] are a recent development and, although provision is expanding rapidly, it is still patchy. These programmes[63,64] aim to increase parents' awareness of children's emotional needs, to develop parents' skills in meeting those needs, to promote parental well-being and prevent or reverse the development of emotional and behavioural problems in childhood. The commonest model is for groups to meet for two hours a week for 10 to 12 weeks. Although programmes may be run by health visitors or social workers, many are provided by non-government organisations, supported on grants from health or local authorities, central government or charitable donations. Other non-structured groups may be provided to support parents of children with specific problems (e.g. disability or chronic disease, or parents whose child has died), often combining support with fundraising activities. Drop-in centres providing social support and access to information and training, either as part of a more extensive parent support programme or on their own, may be provided by non-government organisations (NGOs) and sometimes by social services in high-risk areas.

Structured programmes have a variety of purposes. The earliest programmes were provided by mental health professionals to parents whose children had established behaviour problems, with a view to reversing or ameliorating the problems (secondary or tertiary prevention). Primary preventive initiatives may be targeted at parents living in areas where there is a high risk of behaviour problems. Programmes may also be provided, usually by NGOs, on an open-access basis in community centres, churches and schools, addressing the more ambitious population-wide health promotion goal of actively promoting emotional well-being in parents and children.

Costs

Prevention is implicit in all the work done by health visitors, and it is almost impossible to cost their various tasks separately. The overall mean cost of health visiting per PCG (now PCT) in four study districts was £510 000 (range £229 000 to £298 000), and there was a weak correlation with deprivation scores.

School programmes

In school-aged children, most successful health promotion programmes are multi-faceted, aiming to reach out to parents and the wider community as well as to children, and in addition changing the school environment.[65] Specific topics such as smoking prevention, healthy eating or sexual health can be tackled, but the most popular approach, namely the health-promoting school, is holistic (*see* Appendix 7).

School health promotion programmes may generate demand for and be complemented by appropriate individual health care. Some teenagers are happy to visit their GP for sexual and mental health advice, but many feel anxious about privacy and confidentiality in general practice premises. These considerations have prompted the creation of adolescent drop-in clinics in schools, primary care settings or other community venues.[66] Collaboration with primary care and family planning services is important.

Costs

The current SHS costs from £250 000 to £350 000 per PCG (now PCT) in the four survey districts, Of this, roughly half is spent on school nursing and half on doctors, administrative staff and others.

Child public health: services which aim to influence the macro-environment

Child public health is defined as health improvement for children achieved through the organised efforts of society. This is a shared role between public health and CCHS. The amount of time devoted to child public health varies widely from one district to another. In the context of CCHS it involves the following.

- The immunisation co-ordinator role: The tasks are summarised in Appendix 8.
- Child health advocacy: This is making the case for changes in services or social policy which would enhance health. Child health advocacy, and professional and public education on child health concerns, can help bring about improvements in the macro-environmental determinants of children's health. The level of involvement of CCHS in these activities varies widely between individuals and districts.
- Contribution to the development of multi-faceted, multi-agency health programmes: This involves working with local authorities, community groups, schools and non-government organisations (sometimes seeking financial support for the latter) to develop health-promoting policies.
- Management of CCHS staff and budget: In most districts this falls to CCHS even though some of the staff work in primary care teams. One person may have overall responsibility for staff, provision and long-term planning.

Disability services

The services available for children with a disability are considered under three headings: primary prevention, secondary prevention and tertiary prevention. The last of these is the main focus of discussion.

Primary prevention

Although better obstetrics, genetic expertise and better health care all play a part, the majority of severely disabling conditions (cerebral palsy, mental handicap, congenital deafness, etc.) are not yet preventable. Birth asphyxia is not the only or the main cause of disability, but is important both because of litigation and because it may to some extent be preventable.

Secondary prevention

The role of community services and primary care in early diagnosis and referral has been discussed earlier in this chapter. There is ample evidence that parents value an early diagnosis of disabling conditions in their child, even if this does not lead to an improved outcome.

Tertiary prevention: care of children with disabilities and developmental problems

The public health overview of services for disabled children

Service provision for disabled children encompasses a number of activities designed to meet the needs of a wide range of ages and problems. These include early identification, a child development team, an audiology programme, links to schools and the Child and Adolescent Mental Health Service (CAMHS), use of tertiary and specialist services, and a range of other community services. A public health overview of needs, referral pathways and information, and a management structure, may be part of the service. The Children Act 1989 calls for multi-agency planning, particularly with regard to shared responsibilities such as early diagnosis and intervention, respite care, expensive residential placements and equipment. The term 'Child Development, Disability and Rehabilitation Service (CDDRS)' has been recommended recently by several professionals in the field, since it can encompass all aspects and models of care.

District Handicap Team

The term 'District Handicap Team (DHT)' was introduced by Court.[67] The DHT may provide the planning and the overview referred to above, though in many districts it focuses only on children attending a child development centre (*see* 'Child Development Teams' below).

Child Development Teams

In the majority of districts, pre-school children with high-severity, low-prevalence conditions are assessed and often treated in a special centre where parents can access all the services they need and professionals can share information and skills. The original title, Child Assessment Centre, has been changed to Child Development Centre (CDC) to emphasise the treatment role. The term 'Child Development Team (CDT)' is now often preferred, first because not all teams operate from a Centre and in rural areas a peripatetic model is often more appropriate than centre-based care (although a team needs a base to meet, store and repair equipment, etc.), and secondly, because school-age children often receive their medical and therapy care from the same staff but at school or at home rather than in a CDC.

Variability in the Child Development, Disability and Rehabilitation Service

The CDDRS usually includes a consultant community paediatrician and one or more of each therapy discipline. Other specialists are recruited to deal with specific problems (*see* Appendix 9). There are startling variations in activity, in the composition of the core team and the availability of specialist inputs, and often there is a lack of any coherent pattern in philosophy or operational policy.[14,68–73] CDTs vary widely in the route(s) of access and referral, the services offered, and the diagnoses, disabilities and age range of the children seen. Some teams care for all forms of disability, whereas others focus on those with severely disabling conditions and exclude (either explicitly in policy statements or, more often, by default) children with acquired lesions, such as traumatic brain or spinal cord injury, and those with non-neurological disorders. Some provide only for the under-fives, whereas others offer support and advice until transfer to adult services. Furthermore, the alternative provision for those children not served by the team is often ill-defined or non-existent. Management arrangements for deciding, for example, how children with high-prevalence, low-severity conditions should be assessed, and for planning the service as a whole, are often weak. The value placed on teamwork, the extent to which parents are involved in case reviews and the readiness to share reports with parents all vary widely.[69,71,74]

Audiology services

Appendix 10 sets out an overview of audiology services. The staffing and economic implications of universal neonatal screening (UNS) are currently being reviewed following publication of a systematic review.[75] (*See* www.nhsp.info for information on the newborn hearing screening programme.)

Community-based services

Children with high-severity, low-prevalence conditions receive therapy and medical support within school. This is easy in special schools or units but more difficult for disabled children scattered among many mainstream schools, and has considerable resource implications for health care provision by nurses, therapists, etc.

Children with low-severity, high-prevalence conditions are often managed entirely in a community setting (health centres, clinics, day nurseries, nursery schools or at home) by therapists, clinical psychologists and community-based paediatricians.

Services shared with other agencies

Health professionals work with social services and education to provide other services. Respite care is an important service for many families and takes several forms, but varies widely in quantity and quality. Parents and children differ in their needs and want a choice of the following:

- hostel/home run by social services with health support or advice
- placement with a family in the child's home district for one or several nights (e.g. 'Share-a-Family' scheme)
- visiting carer looks after the child at home
- specialised facility if the child's needs are very complex; may also provide palliative or terminal care along hospice lines
- hospital ward, alongside sick children or in a specially designated unit or room; only appropriate for severe problems which limit use of other facilities.

The provision of appropriate education

This is the responsibility of the local authority. Health services play an important supporting role (*see* 'Support and advice to the Local Education Authority: the school health service' above). The 1994 Code of Practice (revised in 2001) and the Children Act require that agencies should co-operate to provide the best care for children with special needs. Pre-school programmes such as 'Portage' (a home-teaching package) are usually provided through the education authority,[76] although some are jointly funded or share resources between agencies. Therapists support Portage programmes for children with complex problems. The PCT may make a contribution to the cost of residential care and education of children with complex problems. The health service is responsible for providing medical evidence and for monitoring of children requiring assessment under the Education Act ('Statementing', *see* 'School-age children: support and advice to the Local Education Authority' above), and contributes to the transition process when the child reaches the age of 14 years.

Child protection

The Child Protection Service deals with abuse and neglect affecting disabled as well as able-bodied children. However, children with disability are at increased risk of abuse. North American data suggest a 50% higher risk compared to non-disabled children. Those with more severe disability and with communication problems are particularly at risk. Peer abuse in residential care can be a significant problem.[34] Disabled children who are looked after require statutory assessments.

Costs

There are no detailed data on the costs of the service as a whole. A cost analysis is a difficult undertaking and a cost–benefit analysis even more so, for several reasons.

- There are a great many disabling conditions, of varying severity.
- Multiple agencies are involved (the NHS, social services, education and the voluntary sector).
- Within the NHS, many disciplines are involved.
- It is difficult to measure the volume and effectiveness of interventions offered or needed.
- Reduced family stress, improved coping mechanisms and raised quality of life are as important as changing the child's physical health status.

In 1991, 78% of districts had some form of CDC, and of these, half also functioned as District Handicap Teams. The staffing and activity levels varied widely. Paediatrician sessions ranged from full-time to one session per month. One-fifth of CDCs would only see children under the age of five. Fifty-nine per cent of CDCs had no adult service to which they could refer their patients when they became adults. By 1998, most districts had some form of CDT. Less than a third offered a comprehensive service throughout childhood, while 70% mainly served under-fives with some other team providing for school-aged children. Over 50% of teams included a paediatrician, speech and language therapist, physiotherapist, occupational therapist, social worker and health visitor. One-third of teams included staff from social services and education. There was also wide variation in the number of specialist services provided within the team. For example, one-fifth offered a head injury service, and one-sixth offered a dyslexia clinic. There was similarly considerable disparity in frequency of team meetings, management arrangements, and the degree of parent involvement in service planning. Staff account for by far the largest part of the total cost of a disability service. Table 5 outlines the case load and Table 6 summarises the data on staffing. Taken together, the data suggest[70] that current per capita expenditure on services for children with disability must vary substantially between districts, perhaps by a factor of three or even more.

There are some data on equipment costs for children with high-severity, low-prevalence disorders. The estimated cost is £1070 per 1000 children (total population) aged 0–19 years. Of this, £341 is for communication aids and £729 for physical disability equipment (1997 figures).[77] There are no comparable data for shared educational or respite care placements.

Table 5: Estimates of case load.

Condition	Available incidence/ prevalence data	New cases per year in district with 1 million population	Case load in district with 1 million population
Cerebral palsy	2.5 per 1,000 births	25	500
Neural-tube defects and hydrocephalus	Varies from 0.4–2 per 1,000 births	4–20	80–400
Duchenne muscular dystrophy	1 per 3,000 male births	2	40
Severe learning difficulties	3.7 per 1,000 children	37	740
Moderate learning difficulties, developmental delay, etc.	2–3% of all children	200	4,000
Specific reading disorder (e.g. dyslexia*)	Said to affect at least 2% of population; mainly present between ages 5 and 10 years	200	1,000 active cases, i.e. aged 5–10 years
ADHD	1% of child population – boys > girls	100	500 active cases, i.e. aged 5–10 years
Epilepsy	6–12 per 1,000 children	60–120	1,200–2,400 cases in district; half active, half in remission
Permanent hearing impairment	Per 1,000 births; 1.3 per 1,000 children aged 5 years (includes acquired hearing loss)	13	260
Autism	1 in 2–3,000 births	4	80
Autism spectrum disorder	2–4 per 1,000 births	20–40	400–800; variable improvements over time
Long-term or permanent speech, language and communication disorders, excluding autism	2–5 per 1,000 children aged 5 years	20–50	At least 100–250 active cases but rate and extent of resolution vary widely
Blind and partially sighted (excluding multiple disability; ‘cortical visual impairment’)	0.7 per 1,000 children	7	140
Traumatic brain injury	160 per 100,000 children per year: 29 with permanent disability	58 with permanent disability – varying degrees	No data available

* Dyslexia or specific reading disorder is an example of the conditions known collectively as specific learning disabilities. Prevalence figures vary depending on definitions. Other examples include specific developmental motor co-ordination disorder.

Assumptions: 1 million people; one-fifth (200 000) in the age group cared for by paediatricians.

These figures are approximate, as data are scarce and data on *active* case numbers are very few.

Most disabling conditions are recognised within a year or two of birth and are present throughout childhood.

Exceptions: Traumatic brain injury is more common in older children. Mild learning disability, dyslexia, language impairment and ADHD are unlikely to present in the first two years, sometimes improve over time and may need little NHS input during the teens. Case-load estimates are correspondingly less reliable.

Death rates in the paediatric age group are too low to affect these estimates.

Table 6: Estimates of workforce requirements.

Post	Minimum	Mean or median	Upper end of range	Notes
Consultant paediatricians with interest in neurodisability	4	7	12	I
Non-consultant career-grade paediatricians	10	15	20	I
Physiotherapists	10	20	30	II
Occupational therapists	6	13	20	III
Speech and language therapists	30	50	90	IV
Clinical psychologists		13		V

The wide range of figures shown here is partly explained by the extent to which hospital-based paediatricians, paediatric neurologists and tertiary centres (neurology, rehabilitation, acquired brain injury, etc.) contribute to the care of the various patient groups listed above, by differences in the contribution of primary care, and by varying levels of input from other staff such as community paediatric nurses, liaison health visitors, personal assistants, etc.

Sources:

Establishment in WTEs (corrected to a population of 1 million people) as observed in unpublished surveys, supported by various documents[78] and reports as follows:

- The British Association for Community Child Health[20] recommended a total of 16 WTE career-grade staff per 1 million population for disability services (i.e. excluding other aspects of CCHS as set out in Section 1).
- The Association of Chartered Physiotherapists recommendations are based on case-load management. Extrapolation suggests that this approximates to the upper end of the range in the table.[78] However, some therapists also provide a service for hospital patients (intensive care, orthopaedics, etc.), so direct comparisons are difficult.
- The National Association of Paediatric Occupational Therapists makes no formal recommendations for staffing levels.
- Ideal speech and language therapy provision was suggested as 6 per 100 000 population by Quirk in 1972 and as 26 per 100 000 (all ages and service needs) by Enderby and Davies in 1989. The current figure is closer to 6. The Royal College of Speech and Language Therapists recently reviewed these figures but no longer makes any specific recommendation.[79]
- In the absence of other data, this figure is based on the guidance of the British Psychological Society that there should be at least one clinical psychologist working with children and families per 75 000 population, but this does not include more specialised input for particular services, e.g. disability.[78]

References

- Lloyd-Evans A. *Child Development and Disability Group. Standards for child development services.* London: British Association for Community Child Health/Royal College of Paediatrics and Child Health, 2000.
- British Association for Community Child Health Working Group. *Community Paediatric Workforce Requirements to Meet the Needs of Children in the 21st Century*. London: British Association for Community Child Health, 2000.
- van der Gaag A. *Communicating Quality. 2. Professional standards for speech and language therapists* (2e). London: Royal College of Speech and Language Therapists, 1996, p. 273.

Mild and moderate psychological disorders

Health services for young people with mild and moderate mental health problems are commonly provided by more than one provider unit in any one district. There may be contributions from primary care, community and hospital paediatrics, child mental health workers, clinical psychology, child and adolescent psychiatry, learning disability psychiatrists and, for older adolescents, adult mental health services. Moreover, services relevant to child and adolescent mental health are provided by several agencies: health, education and social services as well as the voluntary sector. Historically there has been poor co-ordination between all of these, and a tendency to duplicate each other's work.

The specialist Child and Adolescent Mental Health Services (CAMHS) are thought to see 10–20% of children with mental health problems and within those children seen in CAMHS, 25% will have their clinical problem rated as less than severe.[38] This suggests that most children with mild or moderate psychopathology are likely to be seen by other agencies, if at all. The ONS survey[36] indicated that for the more severe category of mental disorder, those agencies included primary health care teams, community paediatricians and, within education, educational psychologists, and it seems likely that the same would be true for in seeing children and adolescents with mild and moderate psychological pathology. The development of tier 2 services within CAMHS, which one might expect to be relevant, is still at an early stage.

6 Effectiveness

Assessing the effectiveness of CCHS activities is difficult, and much of the evidence is of indifferent quality (*see* Box 8).

Box 8: Problems in assessing the effectiveness of CCHS.

1 CCHS is a network of activities involving several different disciplines.
2 CCHS activities overlap with those of acute trusts and of many other agencies.
3 The important outcomes need to be measured many years into the future.
4 The need for preventive services is assessed by professional opinion, not demand, as public awareness is limited.
5 The effectiveness of any CCHS action (at individual or community level) may depend on other actions (synergy) that are not under the control of the CCHS.
6 Randomised controlled trials are difficult to apply to complex interventions such as those offered in the CCHS.
7 Collection of information to monitor the CCHS is complicated by the many sites where the services are delivered.

Economic analysis of preventive services with far-reaching aims, such as the majority of CCHS services, is complex. What might be achieved is as likely to be constrained by what society is prepared to invest as by potential effectiveness or impact. Consideration of cost-effectiveness has however been severely hampered in these services by lack of information on costs as well as on effectiveness (as in earlier sections, a PCG [now PCT] is assumed to have a population of 100 000).

Children who are the primary responsibility of social services departments

Much of the work done in support of social services is required by legislation and official guidance. It is a response to situations that society considers to be intolerable. There is only limited evidence about the long-term impact of these services. Legislation and official guidance may have inhibited experimentation and research.

The assessment of abused children can itself become abusive. This is less likely to occur if it is done by those with appropriate skills and training. Little is known about the value or diagnostic accuracy of examinations for abuse other than sexual abuse. Reliability is generally assumed to be high where physical abuse is concerned, but may be less so for emotional abuse or neglect.

Good practice in assessment and follow-up of sexually abused children includes provision of reassurance, exclusion of sexually transmitted diseases where appropriate, and provision of emergency contraception if indicated. Clinical experience in psychotherapeutic practice suggests that abused children would benefit from prolonged therapy to prevent future mental health problems,[80] but in view of the potential cost of such services and the possibility that they might have no benefit (or could even be harmful), they merit further research. Appropriate training and better co-ordination between existing agencies, notably child psychiatry and psychology and social services, might be a more effective way to provide such services than the creation of completely new teams.

The outcomes for children who suffer chronic abuse, or are looked after, are poor in terms of mental health and adjustment to adult life. Adoption outcomes are also often disappointing.[34] The potential benefits to be obtained from effective intervention are correspondingly large, but little information is available on the value of intervention at its current levels (*see* 'Organisation and provision of health promotion and preventive services which influence the micro-environment' below for effectiveness of preventive services).

- Size of effects: unknown. Quality of evidence: III.

Support and advice for Local Education Authorities: the school health service

Table 7 (*see* overleaf) summarises the effectiveness of the many activities included in school health services.

The routine examination by a doctor of all school entrants at age five is of doubtful value. Most of those who have carried out studies of this programme appear to have taken for granted that the detection of 'defects' is beneficial, and have focused their investigations on whether defects can be detected, but for many of the commonly identified conditions the need for and effectiveness of intervention are far from certain. None of the studies identified in a recent review were able to address the question 'Do school-entry medicals improve health?' Data from school-entry medicals have been used in the past by public health practitioners to identify health needs, but are no longer an efficient way to establish such needs.

Routine examination of all school entrants might be justified in areas where delivery of pre-school primary health care is poor. It could be useful to identify, perhaps by questionnaire, those children who have long-term health problems of importance for their schooling and those who have had little or no health care before starting school, e.g. recent immigrants and children from travelling families. Even in these circumstances, this function might be provided more effectively through the development of primary care rather than through the school medical service.

In most districts the school-entry medical examination has been replaced, on pragmatic grounds, by a school-nurse health assessment and interview. The aims have not been articulated any more clearly than

Table 7: Services provided for children of school age.

Task	Justification and aim	Evidence
Medical examination of all school entrants (age group 4–5 years).	Identification of previously missed defects, e.g., congenital heart disease, undescended testes.	Number and significance of defects found uncertain, but probably not cost-effective.
Developmental examination of all school entrants.	Identification of previously missed or ignored learning, motor or behavioural deficits.	Assessment by experienced person identifies defects, but no evidence that this is more effective than detection by teacher or that it improves outcome.
Assessment of all school entrants in person by school nurse.	Identification of symptoms of ill-health for onward referral. May be combined with health promotion interview and with vision/hearing tests. Opportunity for child and parents to meet nurse.	No evidence of benefit; no UK studies available to assess current practice, but no reason to expect as good a yield as examination by doctor. School nurse not well known to family in one study.
Assessment of school entrants by school nurse using questionnaire to parents to select those who should be seen in person.	As above; also to identify children with no previous medical care and those not registered with a primary care team.	No hard evidence, but a low-cost activity which is a necessary prelude to provision of primary and preventive care.
Vision test at school entry.	Detection of refractive error, squint and amblyopia by visual acuity test with each eye separately.	Adequately trained staff can produce acceptable results; benefits modest, but school entry is first time 100% of children can be reliably tested for vision defects.
Hearing test at school entry.	Detection of missed, late-onset, mild or unilateral sensorineural hearing loss; detection of persistent middle ear disease.	Number of cases of sensorineural loss very small; natural history and impact of middle ear disease variable and still uncertain.
Screening for scoliosis.	Detection of scoliosis in young teenagers.	Evaluations of programme not favourable.
Height and weight at school entry.	Detection of growth disorders; valuable public health function (trends in height and differences between social groups are a good marker of children's health – included in proposed core data set).	Yield of growth disorders very small, but acceptable false-positive rate.
Vision, hearing and height in subsequent years.	Detection of new-onset disorders.	Yield very low. Older children with refractive error can access optometrist on request. Height monitoring not useful.
Immunisation.	Prevention of TB; rubella and other immunisations when indicated; new programmes; school-leaving booster. Check on children who have missed programme.	Little data on role of school vs. primary care team. In deprived areas, probably more cost-effective when provided through school. PHCT may give better uptake in less deprived areas. BCG should be done in school – inexperienced operators get poor results.

Table 7: Continued.

Task	Justification and aim	Evidence
Medical examination required in connection with the 'Statementing' procedure specified in the 1981 Education Act.	Statutory requirement.	Necessary and useful for children with disabling conditions. Value for children with learning or behavioural problems less certain, but occasional finding of vision, hearing or other medical problem.
Child protection: examination, advice, support, liaison.	Statutory duty within local child protection and ACPC guidelines.	Benefits unknown, but essential role and support for suspected or actual cases is expected by education staff.
Identify and participate in handover of children with special needs to adult services: required by Education Code of Practice 1994, but important even if child has no Statement of Special Educational Need.	Ensure smooth transition into the most appropriate adult service at the right time, with full information to new specialist team and primary care staff.	Good evidence of current defects in system; upsetting to parents; examples of good practice involving community nursing as facilitator of handover.
Medical, psychological and social evaluation of children referred by teachers or parents because of problems in school.	Learning problems can be caused by biological or social factors; detailed diagnostic assessment desired by parents but not always available from psychologist.	Medical role in assessing school problems is ill-defined; logical that accurate diagnosis should improve remedial work; extensive anecdotal evidence but little rigorous data. Exception is attention deficit disorder – good evidence of benefit from accurate diagnosis and correct management.
Prepare and support care plan for special needs children in collaboration with Special Needs Co-ordinator (SENCO).	Children with disabilities need health care support in school. This can be provided by the education authority, but the SHS should offer information, support and training.	Need for this service is stressed by teachers and headteachers.
Provision and interpretation of information relating to special needs children, particularly when placed in mainstream schools, and to children with health problems.	Ensure that teachers understand implications of and care for health problems of children in school.	Teachers expect and value such advice from the school health service but complain it is often not available. No evidence as to quality or availability of advice given.
Counselling and consultation service, particularly in secondary schools.	Provision of advice and support for range of problems, mainly for older children and teenagers.	A service wanted by young people, separate from that provided by GPs. Measurable benefits in prevention of teenage pregnancy.
Support to educational social work service; working with parents of children out of school, etc.	Identification of children failing in school and children out of school for any reason. Follow-up to establish reason and assist re-entry to school or other educational intervention. Involves close liaison with educational welfare officer.	Examples of good practice support concept; obvious need for service – potential benefits considerable.

Continued overleaf

Table 7: Continued.

Task	Justification and aim	Evidence
Responding to concerns about head lice.	Advise parents and schools on management and prevention of head lice infestations.	No support for routine inspections; school nurses well placed to advise on treatment by insecticides or mechanical means ('wet combing, with conditioner', 'bug-busting').
Environmental health issues.	Avoidance of cross-infection by poor hygiene in toilets, responding to school concerns about infections, such as HIV, and epidemic diseases, such as outbreaks of meningitis; advice on individual children with infectious diseases such as chickenpox, skin diseases, etc.	Most interventions based on good evidence.
Share policy development for and take part in health promotion and education programmes.	Assist in preparing and teaching lessons on health topics; support staff in healthy school initiatives. Liaise with health promotion specialists to identify topics and resources.	Important role for health staff – initiate, support and contribute to health promotion schemes in schools. Can create opportunities through health promotion for pupils to use consulting/counselling service.
Advice to headteachers regarding the health of children travelling on school journeys or participating in unusual sports.	Reassurance of teachers, avoidance of medical problems away from home.	Uncertain value; serious medical problems need advice from child's specialist.
Provide an informal support and advice network for teachers.	Teachers have many problems of their own for which they might value advice.	No evidence available other than anecdotal reports.
Hands-on nursing care, e.g. gastrostomies, tracheotomies, tube feeding, medications.	May be provided in special schools; task shared with other carers and/or community paediatric nurses.	Valued by education staff, though few data on volume or training needs.
First aid.	School nurses do *not* normally consider it part of their role to provide a first-aid service in schools.	Little evidence, but teachers do value first-aid support and training; may play a part in health education.

those of medical examinations by doctors. A review[81] in 1998 did not identify any studies which could provide evidence of effectiveness, but one study showed that this approach might cost more than routine medical examination of all children. Although the evidence base is incomplete, school-entrant vision and hearing testing, and measuring height and weight, probably constitute the best-buy school-entrant screening at present. The benefits of these programmes depend in part on what pre-school programmes are in place. There is little evidence to support any further screening procedures of all children after the age of five. Repeated measuring of short children is not useful.

- Size of effect: probably D. Quality of evidence: IV.

The effectiveness of school immunisation programmes is kept under review by the Department of Health. Most programmes are universal but there is debate about BCG. Although a few districts with low prevalence rates have dropped the programme, most retain it. Although the incidence of TB was falling, it rose in the 1990s and is now causing considerable concern, especially in urban areas. This rise is related to a number of factors, including poverty/homelessness, increases in refugees/asylum seekers and incomplete treatment. Co-infection with HIV and TB is also a problem. Multi-drug-resistant organisms are a growing concern.[82]

- Size of effect: C. Quality of evidence: III.

Whilst there are no experimental studies of the effectiveness of the school nurse's role in safeguarding the health of children with specific problems, it is well described, thought to be important by school nurses and valued by teachers.[83,84]

- Size of effect: C. Quality of evidence: III.

The added value derived from the medical contribution to 'Statementing' of children has not been systematically assessed. Experimentation may have been inhibited by national guidance and legislation.

- Size of effect: unknown. Quality of evidence: III.

School nurses' involvement in school health promotion raises two issues: (a) the effectiveness of health promotion in schools and (b) the effectiveness of the school nurse's role in this process. These are dealt with in 'Organisation and provision of health promotion and preventive services which influence the micro-environment' below.

- Size of effect for (a): C. Quality of evidence: III.

Neonatal and pre-school child health screening, immunisation and health education programmes

There are two effectiveness issues here, namely the effectiveness of the screening, immunisation and health education programmes and the effectiveness of the CCHS role in that process. The key screening procedures have been reviewed extensively (*see* Table 4). The present programme is pragmatic, based on a best-buy concept that seeks to integrate the limited evidence from experimental research with consumer wishes and professional opinion. There is, for example, still doubt about screening for congenital dislocation of the hips and congenital heart disease, but these programmes will continue until further research is available. Three programmes are discussed in more detail below.

Neonatal hearing screening

For the past 40 years the hearing of infants at 7 to 8 months of age has been tested using the infant distraction test (IDT) as part of the programme delivered in primary care. Despite this, hearing-impaired children are still identified too late for optimal outcomes. Screening of all neonates is now possible and this programme is more cost-effective than the IDT.[75] The delivery and maintenance of an effective neonatal screening programme presents many challenges, and an implementation plan has been developed (*see* www.nhsp.info). The first step will be to ensure that excellent and timely care is available for babies identified in the programme.

- Size of effect: B. Quality of evidence: I-1.

Vision screening

Although screening by orthoptists has been demonstrated to be substantially more reliable and cost-effective (in terms of sensitivity and specificity) in pre-school children than screening by any other professional, there is still controversy about the extent of disability caused by minor visual defects (amblyopia, squint and refractive error), the effectiveness of treatment[85] and the extent of the additional benefit from screening at age three or four as opposed to age five. Trials of treatment for amblyopia are currently in progress. The interim solution proposed pending further evidence is screening by orthoptists for children between the ages of four and five.[27]

- Size of effect for treatment: unknown.

Biochemical and other laboratory-based screening

The neonatal screening programmes for phenylketonuria (PKU) and hypothyroidism (HT) are well established and are cost-effective. However, there are still weaknesses in the system, one of which is the lack of an identified individual to be accountable for the programme. The effectiveness of screening for cystic fibrosis is currently under review. New screening methods have been developed to detect medium-chain acyl CoA dehydrogenase deficiency (MCAD) and glutaric aciduria type 1, but these are not yet provided on a routine basis and studies of effectiveness are incomplete.[86] It is possible to provide reproductive choice for parents at risk of having children with haemoglobin disorders and to reduce the number of births affected by thalassaemia.[87] Effective programmes will include antenatal and neonatal components, review of the care of people with these disorders, and community education programmes which aim to encourage young people to determine their carrier status before conception.

- Size of effect: A for PKU and CHT; C for other potential programmes. Quality of evidence: II-2 for PKU; II-1 for CHT; III for others.

Organisation and provision of health promotion and preventive services which influence the micro-environment

Systematic reviews of holistic home-visiting programmes for new parents, offering general support and skill development, suggest that such programmes can be effective in high-risk groups, reducing the incidence of injuries and the antecedents of abuse and neglect, improving the mental health of parents and children and impacting beneficially on a variety of other outcomes.[28,88,89] Evaluation of their impact on child abuse has been confounded by the increase in identification and reporting which usually accompanies intensive intervention. Evaluated programmes have varied greatly in their target group, their length and intensity, and in the professional background of the visitors. Success is not uniform; it depends in part on programme intensity and length and presumably on many other factors, of which the interpersonal skills of the home visitor may be the most important. Most of the experimental studies of these programmes have been carried out in the USA, where home visiting is not routine practice as it is in the UK.

In the UK, a parent adviser service using home visiting by trained health visitors and clinical medical officers has been shown to reduce behaviour problems and improve parental mental health.[37] The author stresses the vital importance of respectful professional–parent relationships. There is conflicting evidence for the success of the First Parent Visiting Programme on a range of child health outcomes, including nutrition.[90,91] This programme, which involved training and development of health visitors to work in a more empowering and supportive way, together with a structured home-visiting programme covering nutrition, child development and health, was widely implemented in the UK. Whilst the structured programme may no longer be used in its entirety, the training programme has influenced how health visitors work with parents. Health visitors practising this programme observed that it was effective in improving parents' self-esteem.

Non-professional home visiting by community mothers has some benefits.[92] Several lay home visiting support services in the USA[93] and one in the UK have been subjected to an extensive qualitative appraisal and their benefits and limitations clearly described. Lay services support and build on, rather than substitute for, professional skills. More research is needed on these themes, but results are promising. In the UK, home-visiting programmes specific to one issue, e.g. postnatal depression or accident prevention, have been shown to have benefits.[71] Programmes offering advice and support to parents on language acquisition and pre-literacy skills seem effective and are likely to have wider educational benefits.[73]

Structured parent training or education programmes based on behaviour modification using role play, role modelling and feedback can improve established emotional and behavioural problems and prevent their development in high-risk groups.[15] Group-based programmes are not only more cost-effective but also more effective than one-to-one schemes. Programmes based on Adlerian, Rogerian or psychodynamic principles which aim to develop parental self-awareness and self-esteem, together with empathy and respect for their children, look promising.[37] Most currently available programmes are eclectic, combining elements of both approaches. Non-government organisations are the leading providers. Some NGOs offer training to health visitors and midwives. Many of these programmes have been evaluated using qualitative methods, which demonstrate that they are appreciated by parents and that they can improve family well-being in all social groups. The effectiveness of these programmes probably depends crucially on the interpersonal skills of the group leader.

- Size of effect: A/B. Quality of evidence: I1/I2.

There are strong theoretical grounds[94] to suggest that a population approach, offering programmes to all parents, is likely to be the most effective way to prevent problems such as postnatal depression, behaviour problems and child abuse. Whilst universal provision has been the accepted model for child health surveillance for many years, it is not yet accepted as an appropriate model for parent support and training. Current opinion favours a basic programme of professional home visiting for all children, together with a more intensive programme targeted at high-risk groups. Targeting of resources by geographic location can be based on one of several formulae, but these presuppose that objectives have been agreed. Targeting of individuals as high risk, without their knowledge and consent, either on the basis of socio-economic indicators or because of observed characteristics of the family, is no longer acceptable. Secretive targeting can interfere with the effectiveness of these programmes and introduces stigma and patronage to provision.

Mutual respect, professional judgement and negotiation are the best way of assessing which families need and will use professional help, who might benefit from support from the voluntary sector either on a one-to-one basis or in groups, and who can contact professional help when needed. Providing additional support to parents who request it, and offering additional resources to selected high-risk neighbourhoods, are both likely to be good investments.

Some NGOs delivering programmes to parents with widely differing health needs favour universal provision, but do not have the resources to sustain this. If universal parenting programmes were to be offered, uptake would be likely to start at around 10% of parents and increase gradually if those who attended found them helpful. In view of the potential for promoting health, studies of the longer-term effectiveness, population impact and methods of providing these programmes are urgently needed.

Table 7 summarises the evidence of effectiveness for school health services. There are several systematic reviews of health-promotion interventions in schools. Whilst universal programmes are the norm, targeted programmes have also been developed for obese children, pregnant teenagers, and children of divorce. Programmes which enable children to develop new skills – both interpersonal (e.g. self-awareness, communication, conflict resolution) and specific skills (e.g. road crossing, food choices) – can improve a wide range of health outcomes (mental health, emotional well-being, dietary intake, fitness, cholesterol levels, injury occurrence, obesity and, more rarely, substance use and sexual health), but cannot be relied upon to do so in every project. Mode of delivery may be critical. Programmes that gain the commitment and support of all the staff and are delivered to pupils in a respectful, empowering manner are more likely to be successful. Programmes delivered by or in conjunction with trained pupils (peer-led programmes) appear to be more effective in improving knowledge and changing attitudes. Children are sensitive to the discrepancy between the health messages they are taught and the environment and culture of the school. Thus programmes that address the school ethos and environment and include outreach to parents and community are more likely to be successful. Promoting the emotional well-being of children seems to be central to success, together with improving the health and well-being of teachers.[95,96] This is the philosophy of the 'health-promoting school'[97] (*see* Appendix 7).

- Size of effect: B. Quality of evidence: I-1-I-2.

There have been no experimental studies of the school-nurse role in the development of school health promotion programmes or policies, or in classroom teaching, though their input is especially valued by teachers who feel uncomfortable with the subject matter. Health promotion is a role for which few nurses are trained, but many have adopted and developed it. Time constraints limit involvement as there is at most one school nurse for one secondary school and often the ratio is lower. School nurses who are not known to staff and pupils and are unaware of the health promotion programmes running in the schools are unlikely to be able to fulfil this role effectively.

The aim of adolescent health services is that adolescents should be better able to look after their own health. This includes greater self-awareness, and greater knowledge of the significance and management of minor physical health problems, and of preventive health care. Little is known about why individuals do or do not make use of such services. Consumer satisfaction can be assessed directly by the extent to which the service is used. In one survey,[98] teenagers rated the following as important in primary health care facilities, in priority order: absolute confidentiality; access to advice over the telephone, if necessary without giving one's name; written information from the health centre; friendly and welcoming approach; notices and magazines suitable for young people. A drop-in type of clinic service which is friendly, practical, non-judgemental and above all confidential is likely to be well used – but such a reputation can take a year or more to develop. Good working relationships with primary care teams and other specialist services are essential. Primary care teams need to create a climate in which young people know that they can see a GP with complete confidentiality.

The best evidence of effectiveness in adolescent health care is in prevention of unwanted pregnancy.[99] Although teachers are required to undertake some sex education, they are not permitted to offer advice on sex or contraception to individual pupils. Government policy is that health and education professionals should be 'involved in the development of the school sex education policy' and that 'Teachers should take account of . . . the contribution which . . . health professionals can make'. A teacher approached by an individual pupil for specific advice on contraception or other aspects of sexual behaviour should 'encourage the pupil to seek advice from his or her parents and, if appropriate, from the relevant health service professional (for example, the pupil's GP, or the school doctor or nurse)' (Circular No. 5/94. *Sex Education in Schools*).

CCHS can provide special adolescent clinics either in schools, in primary care or in specialist community clinics (*see* Appendix 11). Both schools and individual pupils value access to a school nurse with counselling skills, though opinions differ as to whether this is best provided within the school campus or outside – probably there is a place for both. Little is known of any longer-term outcomes, but logic suggests that provision of what teenagers want would be the first step to an effective service.

Several of the health promotion interventions described in this section might have a delayed beneficial effect on health, but most of the studies reported here are based on short-term outcomes. The long-term follow-up studies of one US, high-risk, home-visiting programme have shown important benefits to mental and social well-being (criminality, employment, psychiatric diagnosis) which are very likely to be associated with improvements in adult health.[29]

Child public health: services which influence the macro-environment

Practical experience and experimental studies of public health interventions have demonstrated that effectiveness depends on multi-faceted multi-agency approaches. Individual interventions suitable for evaluation in trials may prove ineffective on their own, yet can be an essential part of a public health programme. Because public health interventions are so complex and experimental studies so expensive, the evidence base for public health is often to be found in observational studies of epidemiological trends and social analyses rather than in experimental studies.

Advocacy on behalf of children – making the case for change at societal level, like the banning of tobacco advertising – can overcome even powerful commercial vested interests, but this may take many years. National and local road safety services have delivered a remarkable reduction in car injuries in spite of a dramatic increase in traffic. They have been less successful in reducing childhood pedestrian injuries, where much of the downward trend may be the consequence of a more constrained and sedentary lifestyle among children.[30]

The school health services and the maternal and child health services were both public health interventions introduced at the beginning of the twentieth century. Collectively they have contributed to a dramatic improvement in the physical health of children and subsequently that of adults. It is, however, impossible and probably inappropriate to attempt to measure effect size or tease out the relative contribution of the different components.

The development of the immunisation co-ordinator role has played a part in raising childhood immunisation rates to their current high level, though other changes such as paying general practitioners based on their immunisation uptake rates have also contributed.

- Size of effect: A/B. Quality of evidence: II-2/III.

Effectiveness of services for children with disabilities

Children with high-severity, low-prevalence disabilities

Few disabilities can be 'cured'. Even major surgery is only an incident in the life of the disabled child. Very small gains can take a long time. Nevertheless, parents of disabled children have well-defined expectations of the health service. Measurements of the effectiveness of disability services can be undertaken in several ways:

- the impact of one particular intervention
- overall assessments of quality of the child's life or family functioning, parental satisfaction, adjustment and coping
- measuring processes of care – as a proxy for quality of life and patient satisfaction outcomes.

All three methods have been used in an attempt to evaluate the effectiveness of the care provided for severely disabled children.

Individual interventions

For children with severe disabling conditions, such as cerebral palsy, therapy aims to prevent deterioration and deformity (which otherwise are inevitable), to enable the child to make optimal use of residual skills, to assist the family to understand the child's problems and handle him in the best possible way, and to encourage the family and other carers to focus on quality of life and participation, rather than become obsessed with individual goals that are often unimportant and unachievable. No treatment has been shown to cure cerebral palsy or dramatically improve outcome, but some controlled studies have demonstrated modest functional gains over relatively short time-scales, and there is consensus that physiotherapy prevents or slows progressive deterioration and deformity.

The best known systems are the Bobath method (a method of physiotherapy and handling which requires skilled support from a trained therapist) and the Peto method of conductive education (which involves a holistic approach to education, therapy and daily living). No advantage of either system over the other has been demonstrated and there is little evidence as to the optimum frequency or intensity of therapy. The Peto approach is attractive to parents and many therapists because it involves a day-long routine, thus to some extent avoiding the issue of how much hands-on therapy is optimal. In addition there are several non-orthodox packages which are not offered through statutory agencies. Parents often feel that they must explore these. One such system has been investigated with the co-operation of the staff.[100] In the absence of any evidence that such systems are superior, and the low level of biological plausibility of some of them, there seems little reason to prefer them to the more conventional approaches available within the NHS and the education services.

Speech and language therapists guide the development of communication skills, and where necessary introduce augmented methods such as sign or symbol systems, or electronic equipment. Randomised trials of such methods have rarely been attempted, but observational measures of communicative function show that considerable gains in communicative capacity can be made. Children with cleft lip and palate do better if managed by a specialist team.

In children with communication impairment due to primary language disorders ('childhood aphasias'), therapy, augmented communication and special education, together with anticonvulsant medication in certain rare conditions, improve communicative skills and adaptation though they rarely produce complete resolution of the disorder.

Autism has been the subject of innumerable interventions and trials, both orthodox and alternative. Behavioural management and appropriate education improve quality of life for the child and their family, though dramatic changes in outcome are rarely achieved.

Intervention in children with moderate, severe or profound hearing impairment consists of amplification (by hearing aid or cochlear implant), education and parent support. This is a highly effective programme with substantial differences between the language skills of those receiving early intensive management and those not so fortunate.[75]

In children with visual impairment, low vision aids, education and parent guidance support greatly improve function. In addition, early intervention may prevent the autistic-like deterioration of behaviour and personality (so-called developmental setback) sometimes observed in these children (Salt A, unpublished data).

Areas of uncertainty include:

- for disabled children, how to measure changes in quality of life resulting from therapy and other interventions
- the optimal level of hands-on input by physiotherapists, speech therapists and occupational therapists, and the extent to which parents can and wish to acquire these skills
- the indications for and benefits of surgery for threatened hip dislocation and for scoliosis in children with cerebral palsy and other disabling conditions

- the benefits of investigation in a gait analysis laboratory, in children with cerebral palsy, prior to multilevel surgery in children with diplegia
- the optimum use of new treatments, e.g. botulinum toxin and intrathecal baclofen infusion for spasticity, neuropharmacological interventions for a range of developmental disorders
- the value of intensive rehabilitation services for children with acquired severe brain injury.

Overall measures of parent satisfaction

In the past, parents have commonly been very critical of the services available for their disabled children, and their views helped to formulate the Charter[22] set out in Appendix 2. Rosenbaum found that parents' top priorities were true parental involvement in assessing information, providing care and decision making, education and information about the condition and the services, treatment and evaluation of progress, care co-ordination between agencies, continuity of care, and a family-centred approach. The quality of 'news-breaking' could be improved and this resulted in greater parent satisfaction.[101] Key factors are the empathy of the professional and the clarity of explanation. Parental assessments of these aspects of the first consultation correlate with long-term parental satisfaction and mental health.

Processes of care

Effectiveness of services can be described in terms of overall parent satisfaction,[97,102,103] but as parental satisfaction is related to processes of care, these can be measured as a proxy. Qualitative studies involving interview data and checklists based on standards of care derived from research and professional consensus (*see* Appendix 2) enable quality of service to be assessed. In such studies, the same themes recur – clarity and adequacy of information when the parents want it, sharing in the planning for the child's present and future needs, being treated with respect, and wanting professionals in different agencies to work together.

Several strands of evidence indicate that access to and use of services are an important issue for parents. For most disabled children, the first important contacts are made with the health service rather than with education or social services, but under the Children Act 1989, the social services are expected to 'provide services for children with disabilities which are designed to minimise the effects of the children's disabilities and to give them the opportunity to lead lives that are as normal as possible . . . every effort should be made to work collaboratively in teams and multi-agency structures in order to avoid the creation of separate and segregated services'.

Each family needs an individual package of care. In the USA this is called an 'Individual Family Service Plan'. Someone has to organise and manage this. The concepts of 'case manager', 'care manager', 'care co-ordinator' and 'key worker' are still evolving alongside the changing role of the social services and, more recently, the notion of partnership with schools. Models differ in the extent to which they are obliged objectively to balance advocacy for the individual child with the needs of other children and the resources available. Parents value the key worker system, particularly with home visiting, and they prefer workers to be proactive in contacting them, rather than leaving it to the parents to initiate each visit.

Low-severity, high-prevalence conditions

Treatments or interventions for children with delayed language development, mild or moderate learning disabilities, clumsiness, etc. are high-volume services which explicitly set out to 'treat' the disorder rather than improve quality of life, as is the case with severe disability. They must therefore be judged accordingly – parent satisfaction is not a sufficient yardstick of success.

A systematic review of speech and language therapy[73] suggested that therapy is effective for children with language delay. For language content, the effect size is greater for protocols that involve carers than for those that rely on professional input alone. Primary prevention by identifying children likely to experience language problems in the first year of life has been adopted in some districts. There are insufficient data to justify a wholesale adoption of such methods at present, but what is now known about language and child development can be incorporated into primary prevention such as the Sure Start programmes, under the guidance of therapists and psychologists.

There is one systematic review (unpublished) of occupational therapy for children with clumsiness or learning problems. Many studies claim benefit, but there are insufficient data to draw generalisable conclusions. Neither the cost-effectiveness nor the coverage of children potentially able to benefit has been adequately investigated. Occupational therapy services often have difficulty meeting those needs where their skills are most essential, such as in seating and daily living assistance for severely disabled children.

Care of children with attention deficit disorder and with a range of emotional and behavioural problems is often shared between paediatric and child psychiatry services (*see* below).

Effectiveness of services for children with mild and moderate psychological disorders

Evidence for the effectiveness of services taken as a whole in this area is sparse. There are two broad approaches to treatment interventions:

- a focused problem-solving approach that targets a specified symptom
- a general, supportive, psycho-educational approach that aims to increase the general competence of parents (of younger children) or personal adjustment (for adolescents).

There is evidence for the effectiveness of both in particular areas. Sleeping and feeding problems in young children respond best to focused work using a behavioural approach.[104] Aggressive behaviour in the same age group can respond to enhancement of parenting.[105] Findings vary according to whether there is specific or polymorphous presentation of problems. In addition, the success of focused approaches is sometimes lost on follow-up because of the overwhelming impact of continuing psychosocial adversity.[106] Both approaches require little equipment but considerable staff time, though providing written information for parents can reduce this.[107] The general approach of focused interventions is psychological, though interventions using apparatus (e.g. enuresis alarms, video-training) are part of the evidence-based treatment repertoire and require an equipment budget.

There is relatively little evidence that has been derived from randomised controlled trials for the effectiveness of medication in this area of mental health. What little there is indicates short-term benefit only, so is not considered in depth here. For instance, small controlled trials support the short-term effectiveness of sedative antihistamines for sleep problems in young children,[108] and desmopressin for short-term relief of enuresis,[109] but in each case there is little or no long-term benefit. There is general support for the logical use of laxatives in constipation with overflow.[110] Prescribing clonidine for oppositional behaviour is quite popular in North America but lacks evidence from controlled trials. In general, medication is less likely to be used in mild and moderate psychological pathology than in psychiatric disorder, but a small drug budget for any service seeing children and adolescents with such difficulties may be required.

There appears to be a tendency to consider ‘counselling’ an appropriate approach to mild and moderate psychological problems in childhood and adolescence. There is no evidence to support this. The scientific literature on psychotherapeutic approaches to children is sparse and biased towards behavioural treatments, with more studies being devoted to this modality and being carried out by researchers sympathetic to it. Studies of psychodynamic psychotherapy carried out by dynamic psychotherapists which might show a positive treatment effect suggest that subjects in such studies are quite likely to be severely affected and not necessarily mild or moderate in their psychopathology.[111] Work in North America has failed to show an effect for 'traditional' psychodynamic psychotherapy carried out by humanistic–dynamic therapists in a population of children (mean age 10 years) identified by school and peers (rather than parents and health professionals) and probably best considered as having moderate psychopathology.[112]

The psycho-educational approach relies mainly upon general support and guidance for parents in responding to a range of childhood behaviours or emotions. It appears to be a widespread practice, but there has been virtually no attempt to gather outcome data to support its use. In general it seems less effective than short-term focused work.[113]

In view of the sparseness of evidence for particular interventions, it may be as relevant and profitable to focus on the evidence for particular ways of approaching service delivery.

Three issues that merit specific consideration are:

- health visiting
- parenting programmes
- prevention.

Health visiting

Health visitors are well placed to implement a number of interventions relevant to child and adolescent mental health, yet the difficulty in measuring their effectiveness in general has led to some scepticism about their value. There is good evidence for the following practices.

- Prevention of (some) postnatal depression using social support, education and discussion about forthcoming parenthood,[114] and promotion through home visiting during pregnancy of better obstetric outcomes.[115]
- Screening women for postnatal depression using the Edinburgh Postnatal Depression Scale.[116] Training is required to prevent this becoming a mechanical exercise and to find ways round the problem of women who protest their mental health because of a range of fears about what may happen to their baby if they admit to feeling depressed. Postnatal depression has been shown to be associated with minor but potentially significant psychological deficits affecting cognition, attachment and behaviour in the developing child.[117] Some of these are risk factors for child psychiatric disorders, and there is theoretically preventative potential here.
- Treating women with postnatal depression by counselling.[118] Antidepressant medication was not found to be superior to psychological treatment in a controlled study (though both were effective), and it appeared to be less acceptable to mothers.[119]

The role of health visitors in preventing and treating mental health problems of young children directly had been addressed by several studies during the 1980s, with somewhat mixed results. Particular problems arose because teaching skills using a narrow focus on behavioural approaches did not seem to yield expected results,[120] and demonstrable short-term improvements tended to be lost in the face of social adversity over the longer term.[106] Nevertheless, considerable enthusiasm has led to two substantial projects. The approach taken in the Bristol Child Development Programme[121] emphasises education of parents and promotion of joint activities for mothers and children. While this has been subsequently adopted by a number of centres and appeared to confer benefit, the evaluation has been less than rigorous and therefore criticised.[120] More recently, in South London the Parent Adviser Service, a counselling intervention for parents and pre-school children carried out by specially trained health visitors and community medical officers, has been described. A preliminary controlled (non-randomised) evaluation indicates a positive effect and is particularly important because it is claimed that a number of families were seen who would not otherwise have received professional support.[37] Nevertheless, the authors point out that just over a quarter of referred families did not take up the service when it was offered, and that it is therefore not likely to be suitable for all.

Current knowledge suggests that direct intervention by health visitors to ameliorate young children's mental health problems may be helpful, but replicated evidence has yet to be provided. Not all health visitors want to focus on children's mental health issues, but clearly some do. The distance-learning packs for health visitors on postnatal depression published by the Marcé Society[122] and on child mental health prepared at St George's Hospital Medical School[123] are in considerable demand. Stevenson[120] suggested that health visitors could function with various degrees of specialisation in child mental health. In one model the health visitor functions effectively as a child primary mental health worker, but this loses the principal advantage of health visitors – their statutory visiting role for all young children. In other words, some health visitors in a locality receive training and take primary care team referrals, yet continue with a reduced case load of routine family contacts.

Parent training

Given that poor parenting practice is one of the principal risk factors associated with mild to moderate psychological pathology, especially in young children, it would be logical to help parents develop their parenting skills. A number of packages to assist parents in recognising and correcting problematic behaviours in their children are available, and are nearly always based on social learning skills. In many approaches parents are seen in groups. Earlier seminar-style training was disappointing in terms of drop-out rates, but more recently a more democratic approach using videotape-based discussion groups has been shown to be effective in reducing problematic externalising behaviours in young children. The so-called Webster-Stratton model,[124] using her videotapes, has become the best-known method. The original tapes are American and feature young children. Similar packages are being developed in various centres and the original tapes have also been re-dubbed with English accents. Replication of American findings is under way by Dr Stephen Scott's group at the Institute of Psychiatry. The effect is greater if social problem-solving classes for the children themselves are provided in parallel.[125]

Parent training is at the heart of several large-scale prevention programmes in North America, and will be part of many Sure-Start programmes in the UK. In view of the way in which evidence for effectiveness depends upon how it is delivered, implementation should be evaluated and lessons learned over the last three decades heeded[125] (*see* Box 9).

It is also necessary to point out that, contrary to lay assumption, conventional family therapy alters patterns of roles and relationships and does not aim to teach parenting skills, nor is it a method for inserting parenting resources into families that lack them.

Box 9: Lessons from experience in offering parent training as a component of child and adolescent mental health prevention programmes.

- Clarity about what to evaluate: parent skills or child behaviour?
- In prevention, targeting socially disadvantaged families will have little overall impact on population rates because of their relatively low prevalence.
- Consideration of childcare arrangements to allow parents to attend.
- Discussion based, preferably with videotapes, more effective than didactic approach.
- Duration and persistence (e.g. 50 hours total) and follow-up improve maintenance of effect.
- Younger rather than older children.

Prevention

The previous edition of this chapter identified prevention as a research priority, stating that primary prevention efforts had not been very successful. Quite apart from the issue of parent training above, a general understanding of what is involved in child mental health promotion has advanced very considerably,[126] and the importance of the following has been established:

- early intervention concepts rather than prevention as such
- relating prevention and treatment interventions for much mild and moderate psychological pathology
- careful thought about choosing between universal, targeted and selective strategies
- active participant involvement
- younger rather than older children, and the need to relate to psychological development
- adequate volume and persistence of interventions
- nutritional rather than inoculation analogies.

It can be argued that the goal of prevention is the promotion of child mental health through the reduction of symptoms, facilitation of development and reduction of known risk factors. Child psychological pathology is an adverse risk factor for adult mental health problems, both in the affected child and in the child's parents at the time. It seems unlikely that there will ever be a sufficient resource for treatment of all child and adolescent psychological pathology. Therefore the consideration of prevention is sensible. One non-randomised study has shown a reduction in later emotional disorder as a result of an early home-visiting programme.[127] Other studies have found no effect, though these have mainly concentrated on antisocial behaviour.[126] Overall, no study has replicated any finding that a particular prevention programme has been unequivocally shown to stop the later emergence of psychiatric disorder. Long-term funding might well be needed to demonstrate this.

7 Models of care

The 1998 White Paper proposals offered an opportunity to change the structure and relationships of primary care and CCHS. Most health authorities anticipated that health visitors would be allocated to a primary care trust. Primary health care for children, both reactive and preventive, would then be largely provided in the setting of the primary care team and PCT, but with a place for reactive as well as preventive health care for adolescents within or close to schools.

The use of primary school premises for parent support and education in collaborations between health and education services has many attractions. Good practice recommendations suggest that each school should have a named school nurse to provide health advice and support for the education staff, and to contribute to school health promotion services. Individual screening tests might be done by dedicated staff. Liaison between individual school nurses and individual primary care teams is vital, though the relationships are difficult because, unlike primary care teams, schools have geographical catchment populations and school nurses often cover all schools in a pyramid from primary to sixth form. The optimum configuration of management arrangements for the SHS is also not clear, but the aim is for a closer relationship between schools, primary health care teams and PCTs. Purchasing and management of the SHS by the schools themselves is possible, but the resources involved are modest compared to school budgets, and it would be necessary to place firm controls on the use of these funds to ensure that statutory obligations were met, so the apparent increased freedom of choice for schools would therefore be largely illusory.

The New NHS did not alter the statutory responsibilities for child protection services and school health. In addition, an enhanced programme of care for 'looked after' children has been developed within the Department of Health. In view of the complexity of the problems faced by many 'looked after' children and young people, specialist support may be needed. PCTs could contract for provision of these services with a CCHS based in a community trust or (preferably) with a combined paediatric service, or even in the future employ a community paediatrician directly. The contract might include management of the common problems which arise in general practice, but for which a GP may not always have the time or the skills. The need for public health support to PCTs is well recognised, but the optimum model is not yet decided. Some community paediatricians already provide this expertise. Alternatively, child public health issues could be covered as part of this brief if the training of public health practitioners covered child public health. Immunisation and child health surveillance co-ordinators should be well known to the PCT members.

The variable and complex relationships between acute and community paediatric services are beyond the scope of this review. However, there is a strong belief amongst paediatricians that management arrangements which divide children's specialist services between two or more trusts are detrimental to provision of the best and most cost-effective care.

Costs

Cost analyses cannot directly answer questions about effectiveness, but they do raise the issue of equity, which is an important issue in the NHS. There are two principles. Populations with equal health needs should receive the same access to health care (horizontal equity). Populations with greater health needs should receive higher levels of access (vertical equity). The same applies to individuals.

The data collected in the four studies described previously (*see* Section 5) offer a basis on which an equitable allocation of health visiting and school nursing resources could be made within and between districts, though they do not provide direct evidence on the issue of value for money.

Support and advice to social services departments

A PCT may be too small a unit to efficiently provide a full CCHS covering continuing professional development and cross-cover. A district-based central child protection service is probably the best solution. The cost of the designated doctor service is difficult to assess, as it is usually combined with clinical child protection work and second opinions on child protection problems. The size of the district, the policies of the local ACPC, the level of deprivation and the existing infrastructure for training all affect the workload. It had been calculated that the basic minimum 'designated-doctor' duties defined by Department of Health guidance could be undertaken in 0.1 whole-time equivalent (WTE) per PCG. Effective proactive work in planning, prevention, training and monitoring (as envisaged in successive departmental guidance documents) needs substantially more than this, though not necessarily directly related to the size of the district, as there may be economies of scale in planning training and attending liaison meetings.

The variability in costs of child protection services described previously is partly related to deprivation levels, but is also strongly influenced by service patterns. For example, a regular daytime clinic slot for children who are not thriving or are suspected of being abused or neglected greatly reduces 'emergency' out-of-hours work in this field and, by reducing the sense of urgency and panic, benefits children and social services staff as well as the doctors concerned. The observed discrepancy between costs of detection and treatment suggests an unacceptable imbalance between investment in detection and diagnosis, and investment in intervention or treatment.

The adoption panel support requirement had been calculated at 0.1 WTE per PCG (usually a community paediatrician), but it varied between districts according to the local adoption rate. The division of the task between community child health doctors and GPs also varied. A range of 0.1–0.2 WTE per PCG was suggested as a baseline figure (a greater WTE may be required per PCT to reflect the larger size of the population covered by a PCT). These figures do not include those for service development, counselling children who have been abused, and meeting the health needs of 'looked after' children or those fostered privately.

Support and advice for Local Education Authorities

In four districts in the studies described previously, routine health assessment accounted for between 56% and 85% of nursing time. Figure 2 illustrates the correlation between deprivation and the investment in school nursing, and from this it is possible to calculate a level of investment which would be equitable.

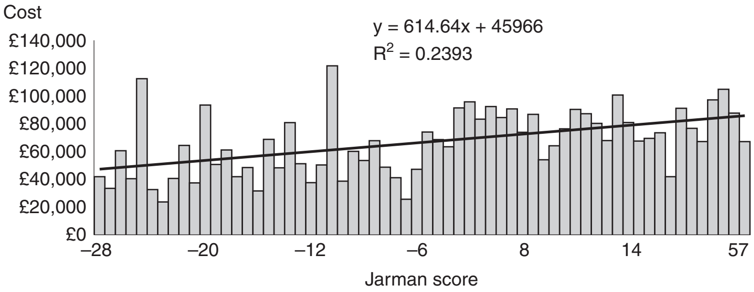

Figure 2: Relationship between cost and deprivation (school nurses).

The cost of fulfilling the statutory duties under the Code of Practice accounts for only a small part of the total SHS expenditure. The minimum health input implied by the 1977 NHS Act has not been defined. In fulfilment of Department of Health guidance, the resources currently attached to school nursing could be used effectively in a number of ways as set out in Table 8.

The commitment of the purchasing authorities to SHS varies widely, as do the expectations of parents and teaching staff. The entire service has been under threat in some districts, but the White Paper *Making a Difference* envisages an important role for this service, and seven elements are needed to secure its immediate future:

- a description of what the service can and cannot provide
- guidance to PCTs about the statutory duties, aims and research base for the SHS
- a commitment from school heads to support the introduction of a modern SHS (including provision of basic facilities such as a private place for children to consult health staff)
- a willingness on the part of the school nurses and doctors to re-examine their roles and, if necessary, produce new job descriptions and training plans
- a long-term commitment to encourage staff development and policy innovation
- a commitment to audit, monitoring and evaluation
- an SHS team leader with management skills and a familiarity with the emerging research evidence.

Some areas of work should be expanded in the SHS, and some might be reduced or discontinued (*see* Table 8 overleaf).

Table 8: Recommendations for school health services.

Task	Recommendation
Medical examination of all school entrants (age group 4–5 years).	No justification to continue except possibly in groups with no documented previous medical care, e.g. newly arrived immigrants or refugees, 'homeless' or traveller families, and possibly parents unable to access standard written information.
Developmental examination of all school entrants.	No justification to continue.
Assessment of all school entrants in person by school nurse.	Of doubtful value.
Assessment of school entrants by school nurse using questionnaire to parents or information from primary care team, to select those who should be seen in person.	Continue, but target the groups with no documented previous medical care as specified above and not those who return completed questionnaires. Targets: identification of all children not appearing on the list of a PHCT; successful referral of such children to care of a PHCT; relevant information transfer (with consent) to teachers about health concerns.
Vision test at school entry.	Continue until pre-school screening established;[27] ensure thorough training by orthoptists or optometrist and monitor quality by spot checks and results reported. Check testing conditions in school. Target: visual acuity record of 100% of children by age 5½. Outcomes: no child to be identified with unrecognised amblyopia thereafter. Reporting mechanism: via optometrists.
Hearing test at school entry.	Continue pending results of research in progress (Nottingham MRC Institute of Hearing Research). Current target: audiogram on 100% of children by age 5½.
Screening for scoliosis.	This is not recommended.
Height and weight at school entry.	Continue. Thorough training essential (inaccurate measurement worse than useless); better data collection and analysis/feedback to ensure quality; clear referral and investigation guideline needed (delays in diagnosis common at secondary-care level). Target: height and weight measures on all children by age 5½. Weight used to calculate BMI for public health use only. All screeners to receive annual feedback on quality and yield. Annual report on district profile of height and BMI by postcode/deprivation index. Seventy-five per cent of predicted numbers of children with growth hormone deficiency and Turner's syndrome to be identified by this age.
Vision, hearing and height in subsequent years.	No justification for hearing and height on present evidence – discontinue. Vision – evidence equivocal and under review – benefits modest but equity an issue. Test at 11 may be justified. Identification of problems depends on patient presenting with symptoms or signs. Inform parents and pupils about free access to optometrist services.
Immunisation.	Continue unless there is clear evidence that primary care team can deliver as high an uptake as the school health service. Target: 100% uptake for at-risk groups.
Medical examination required in connection with the 'Statementing' procedure specified in the 1981 Education Act.	Legal duty – continue. Target: fulfil Code of Practice requirements on turnaround time.
Child protection: examination, advice, support, liaison.	Continue; ensure regular training. Target: all staff to have appropriate training at intervals specified by ACPC.

Table 8: Continued.

Task	Recommendation
Identify and participate in handover of children with special needs to adult services: required by Education Code of Practice 1994 but important even if child has no Statement of Special Educational Need.	A service which can be developed within existing framework – a service to be developed and monitored. Targets: fulfilment of Code of Practice; all special needs children leaving school to have health care plan for their future PHCT and specialist support.
Medical, psychological and social evaluation of children referred by teachers or parents because of problems in school.	Benefits need research; meanwhile, best policy at local level depends on medical skills and other resources available (educational psychologist, child psychiatry service, remedial teaching).
Prepare and support care plan for special needs children in collaboration with Special Needs Co-ordinator (SENCO).	An important health service role which is perceived as being neglected by education staff.
Provision and interpretation of information relating to special needs children, particularly when placed in mainstream schools, and to children with health problems.	Important function, but paediatricians should convey information to schools about medical problems. School health staff might help by interpreting it, but if clear enough this should not be needed. Better training in communication with schools needed for paediatricians. Staff who advise teachers must be up to date with current guidelines.
Counselling and consultation service, particularly in secondary schools.	Current service fragmented and inadequate in many places – a service to be developed and monitored. Targets: all teenagers to have access to a choice of services. Steady year-on-year rise in use of the services. SHS staff to be aware of reasons for all children not in school for more than a specified period. Outcomes: teenage pregnancy rate; mental health referrals; suicide rates; school dropout rates; qualifications.
Support to educational social work service; working with parents for children out of school, etc.	A service to be developed and monitored.
Responding to concerns about head lice.	Ideal solution is public education so that head lice do not cause widespread panic, but school nurses best placed to reassure and educate. Target: steady fall in demands to school for head inspections; fall in use of insecticides.
Environmental health issues.	Although these are the responsibility of the environmental health officer and/or the consultant in communicable disease control, school doctor may advise in such situations.
Share policy development for and take part in health promotion and education programmes.	Vital role is in one-to-one support and advice for pupils. Target: depends on schools – aim should be introduction of health-promoting school philosophy in all schools. Use of health promotion services and resources good measure of effectiveness. Measures of smoking, etc. might be useful if they involve the pupils themselves.
Advice to school headteachers regarding the health of children travelling on school journeys or participating in unusual sports.	Minor issue occupying little time; probably of little value, but valued by teachers.
Provide an informal support and advice network for teachers.	School nurses may offer informal support to teachers with problems but should not be drawn into providing an unofficial occupational health service unless further training is provided and appropriate service agreements set up.
Hands-on nursing care, e.g. gastrostomies, tracheotomies, tube feeding, medications.	An essential service for a small number of children.
First aid.	This is not a school health service function.

In summary, the following suggestions are made.

- Investment should be reduced in routine screening, assessment and health-promoting interviews for those starting school, and school medical examinations. Involvement of parents in school health promotion is better carried out in conjunction with classroom teaching and whole-school initiatives.
- Those screening procedures that remain, the gathering of routine health data about children starting school and the identification of children with problems or with previously inadequate health care should be carried out by staff on a lower grade than current school nurses, with regular retraining and quality checks.
- Responsibility for communication with schools about children with health care needs should rest with GPs, consultant paediatricians or specialist outreach community nurses, although school nurses may help to ensure that the information is understood and acted upon.
- There is no evidence to support any further routine screening of all children after the first year in school (with the possible exception of a further vision screen).
- School nurses' major roles are providing advice and support for teachers regarding pupils with problems and special needs, working with teachers and the educational social work service to help pupils not in school for any reason, and providing an advice, consultation and counselling service for older children and teenagers, both in school and on separate premises.
- Current investment is too small for nurses to take a major role in initiating and planning the implementation of a health-promoting school programme, or in classroom teaching, but they should be members of the planning team and may contribute to classroom work.

Adolescent health services take time to develop and the need and demand are difficult to assess. Given the fact that teenagers make up half the school population, together with the evidence that they want such a service, it might be reasonable to devote at least half the SHS resources to work with older children and teenagers. A planning group that involves GPs, family planning or sexual health staff, health promotion workers, education representatives and spokespeople for the young people themselves is necessary to establish such a service at local level.

Organisation of neonatal and pre-school child health screening, immunisation and health education programmes and organisation and provision of health promotion and preventive programmes which aim to change the micro-environment

These two sub-categories are taken together since the main costs in both services are health-visiting services.

The cost of the Child Health Promotion Programme is made up of six elements:

1. payments to doctors, usually GPs qualified to provide CHS (currently part of the 1990 Contract and set (as of 1997) at £11.75 per child under five)
2. the cost of the health-visiting service, since this is mainly (> 90% in many places) devoted to children and young families
3. the cost of the referrals generated – which is very difficult to estimate
4. the costs of continuing professional development, in-service training and advice to PHCTs
5. the costs of collecting and using data for managing the service
6. additional services, in particular the health promotion team, and various multi-agency schemes funded in various ways, and services provided by NGOs.

Some GPs like to offer most of the surveillance work themselves, but many limit their role to any physical examinations required, provision of facilities for children to be seen and for records to be kept, and management of problems presented as a result of surveillance. In many PHCTs, health visitors carry out most routine reviews and health education and some are learning to do physical examinations. There are a few deprived areas of the country where the perceived standard of general practice is poor and community medical officers offer an alternative. However, the number of such places is declining.

Assessing the current costs of health visiting is straightforward, but the optimum level of investment is not known because there is no uniform model of service provision. The cost of the health-visiting service varies widely between districts, apparently mainly for historical reasons rather than due to deprivation (*see* Figure 3). Within any one district there is variation in practice and workload, but equity of workload can be improved by formulae that adjust for deprivation and case-load size.[56] In a district with wide variations between the lowest and highest deprivation scores, the minimum differential in resource allocation needed to balance workload was a ratio of 5:4. Thus the case load could be 333 under-fives in the least deprived PHCT and 267 in the most deprived. This figure was an underestimate of the re-allocation needed, because it was based on what health visitors currently do, which is constrained by the need to prioritise and control their work. An alternative approach is to consider what health visitors might usefully do. For example, further rationalisation of the child health surveillance programme could allow a ratio of 3:2.

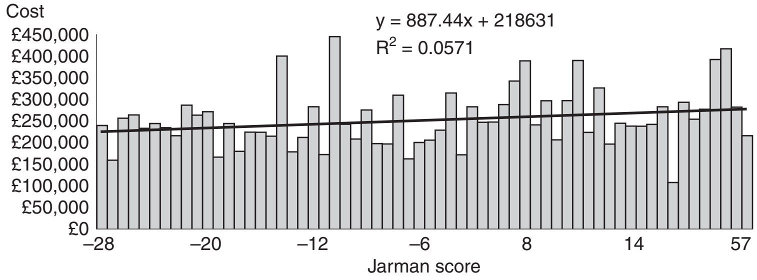

Figure 3: Relationship between cost and deprivation (health visitors).

In a district that has established targeting policies, around 20–25% of health visitor time is allocated to routine work such as the CHS programme. A further 20–25% is devoted to client-led requests for help originating from clients who had been offered the basic programme of CHS only. The other half of the health visitor's time is allocated to clients with identified needs receiving programmes of care. The amount of resource devoted to high-risk support depends on the level of risk at which intensive home-visiting support is offered. Other grades or types of staff can make an important contribution, but it requires considerable experience to identify problems which are unrecognised or concealed by parents. Lay workers are in general best regarded as an extension of rather than a replacement for professionals.

Resources invested in routine health-visiting work could be reduced further by redefining what the CHS minimum service should include. Parents with healthy children and uncomplicated life situations want easy access to their health visitor when they have a problem. They object to difficulties in making contact, failure to reply to messages and failure to provide clinics at times accessible to working mothers.[79] Efficiency might be increased by developing groups for parents to develop emotional awareness and parenting skills, at the same time as offering information about child development and common health problems. No costings have been developed as yet for universal provision of parenting programmes. However, it has been estimated that universal provision of parenting programmes in support of pre-school education, which have considerable overlap with the programmes discussed in this chapter, could be achieved for between £300 and £1800 per child.[78] Given the interest in these programmes from health, education and social services, joint funding of universal provision is potentially feasible.

Changes in health visitor distribution at the level of general practice may cause much disruption for little gain, since many case loads would gain or lose fractions of a WTE. Re-allocation to groups of GPs or PCTs is more feasible and more flexible at that level. An alternative could be a division of duties for some health visitors between case-load work and a role that covers several PHCTs or a whole PCT. For example, some health visitors might wish to retrain in mental health and parent support, and act as tutors and support workers to their colleagues. Others could facilitate the introduction and development of new screening programmes (e.g. neonatal hearing screening and haemoglobinopathy screening) and improve existing but low-quality schemes. Some health visitor time could be used for public health profiling, peer training, development work such as establishing or supporting new parent groups and voluntary schemes and TB control. More research is also needed on the optimum number of outreach nurses and the workload of 'hands-on' home care children's nursing.

Both the Green Paper *Supporting Families*[128] and the Sure-Start programme[129] launched in 1999 suggest that the Government envisages greater involvement of health visitors in supporting at-risk parents. The Sure-Start programme draws on North American research indicating long-term benefits from intensive early intervention with a strong educational focus and the sum of money to be invested in each community is substantial.

Screening programmes provided outside primary care are likely to be directed at national level, organised at 'district' level, but monitored at regional level, with quality-control measures set up and run centrally. A switch to neonatal hearing screening, discontinuation of routine distraction testing and a re-appraisal of the school entry sweep test has been recommended.

Pre-school vision screening is under review. Easy access to a community-based orthoptic service for poor families increases equity and minimises false-positive referrals to the ophthalmic outpatient clinic. Where primary population screening is not attempted, this can be regarded as secondary screening, where the primary screen is identification of parental or professional concerns (whether by question or by screening examination), or as an outreach from the specialist ophthalmology department.

Biochemical screening might be extended to include detection of MCADD and glutaric aciduria by TMS, and possibly other disorders in the future. The role of screening for cystic fibrosis is being reassessed. A good case can be made for screening of at-risk neonates for sickle-cell disorder.

Child public health: services which focus on the macro-environment

A survey of immunisation co-ordinators suggests that for a district of 1 million the role requires 0.4 WTEs. More time is needed whenever there is a 'scare' in the press or a new vaccine programme. For example, an enhanced programme of screening for hepatitis B in pregnancy will require greater efforts to ensure that all babies receive the full course of vaccine.

The input required to deliver the management, advocacy and planning roles is more difficult to quantify. Effective proactive planning as opposed to merely responding to proposals and crises requires a strong commitment of time and energy. Greater investment in this aspect of CCHS might have an important effect on child health and this hypothesis needs to be tested. At least one paediatrician with a public health orientation is likely to be needed per district if there is no other public health doctor committed to children's needs. There is currently a shortage of paediatricians trained in public health and of public health doctors with sufficient paediatric experience to make reliable decisions related to children's health.

Quality management

The effectiveness of the CCHS in the organisation of CCHS screening programmes has not been evaluated experimentally. Many child health screening activities with unacceptable sensitivities and specificities, offering little health gain, were continued longer than was justified due to lack of monitoring and evaluation by the CCHS or public health departments. This will be required in future as part of current Government strategy to improve screening programmes. Monitoring of coverage, timeliness and the quality of the experience for parents (informed consent, access to information, prompt referral for positive screening tests, etc.) should be the responsibility of one named person in each district. This will require improvements to child health IT systems, and there are good arguments in favour of implementing a national database. In spite of the efforts of a national co-ordinating group, each district seems at present to be developing its own ideas, resulting in duplication of cost and effort. The implications of the Data Protection Act in relation to confidentiality have yet to be fully absorbed into practice.

Quality management of health promotion services is complex. The views of the recipients have always been considered important in these services. The parent adviser service is developing some quality measures based on questions such as 'Did you feel respected/patronised by the parent adviser?' Further measures along these lines are likely to be developed over the next decade.

Children with disabilities

There are sufficient disabled children in each district to justify the existence of a CDDRS (for volume and workload estimates, *see* Tables 5 and 6). Most disabling conditions presenting in childhood are lifelong, and support and advice throughout childhood and the teens are needed. The principles underlying disability service provision have been defined in a European forum (*see* Appendix 3).

The optimal levels of staffing should ideally be based on demonstrations of benefit per unit cost but few robust data exist. Service specification and estimates of the volume of service provision are therefore based on a combination of the research reviewed above, quality standards proposed by the relevant professional bodies, calculations of the input needed by children with a range of conditions at different stages of evolution, and observed staffing levels in districts regarded by peers and parents as offering a 'good' service. Table 5 shows the predicted case load of children with disability in a 'typical' city population of 1 million. Table 6 summarises the data on staffing.

The findings from a range of studies suggest that the ideal service has the following characteristics.

- It offers a comprehensive plan for the management of children from birth to 18 or 19 years, with disabling conditions of any kind, whether mild or severe.
- It defines goals for intervention that can maximise the potential for growth and development, increase participation in a range of social situations (rather than achieve specific developmental milestones) and increase the likelihood that the individual with a disability will lead a useful and happy life.[11,130,131]
- It has a consumer/empowerment philosophy of care (*see* Appendix 12) that helps the parents and carers to cope rather than 'de-skilling' them, and considers the needs of the whole family rather than just those of the child. This implies no standard package of assessment or care, but options presented fairly to each family.
- It undertakes regular self-appraisal and strives to meet the standards set out in the Charter (*see* Appendix 2).
- It co-operates with other agencies to ensure liaison over the needs of individual children.
- It has a base from which services are organised and delivered.

- It provides facilities for prolonged assessments when the diagnosis and intervention needs are unclear – ideally, funded jointly with departments of education and social services.
- It provides an effective public health and management group (district handicap team or similar) with participants of sufficient seniority to make and implement decisions for the whole district.[132]
- It includes as core staff a paediatrician, psychologist (clinical and/or educational), social worker, member of each therapy discipline, links with teaching, health visitors and paediatric community nurses, and links with voluntary sector, but develops a team individualised for each family.
- It offers referral to tertiary and specialty services for complex and uncommon problems and a combined clinic setting when multi-disciplinary decisions have to be made.[133] Children who need such services include those with, for example, swallowing and feeding problems, cleft lip and palate, the dual impairment of deafness and blindness, arthrogryphosis, and neural-tube defects (spina bifida).
- It has a secretary/administrator as an easy point of contact for parents, providing a 'single front door', i.e. access to all the services needed without a complex bureaucracy.
- It offers families a key worker or case manager. The key worker can be provided by any of the statutory agencies.
- It ensures a well-planned transition from school to adult life and arranges for adult-oriented services to take over care.
- It undertakes teamwork with child and adolescent psychiatrists and child psychologists to prevent and deal with behavioural and emotional difficulties, particularly in those with severe learning disabilities.
- It provides mainstream services for children with learning disabilities (mental handicap) by the paediatric team and uses a community learning disabilities team as an expert resource (CMHT).[134]
- It keeps a register of disabled children or collaborates with social services register staff and has arrangements to share data between agencies wherever possible, remembering the requirements of the Data Protection Act 1998 (parents' permission for registration must be obtained).
- It has the ability to analyse register data in order to obtain a local profile of disability and need.
- It provides ongoing training for health professionals – a team spirit of learning, keeping up to date and seeking continuous improvement.

A difficult problem in defining the ideal service is to determine and provide optimal therapy. There is constant pressure from parents for more therapy input. Understandably, parents feel that more must mean better. The evidence on this point is unhelpful. A disability service can always absorb more physiotherapy, occupational therapy and speech therapy but, even without substantial extra resources, the service can be improved by:

- better definition of therapy goals
- short programmes with defined objectives followed by a period of observation
- more effective liaison with educational services
- better teaching of parents and carers regarding the methods and goals of therapy
- the use of therapy aides
- provision of secretarial and clerical help.

Low-severity, high-prevalence conditions

The ideal model includes effective case finding (using the mechanisms outlined earlier), shared resources and planning with social services and education (since problems often involve more than one of these agencies), and a developmentally oriented day-care and educational system that can meet the needs of all young children and, in particular, those with special needs. In many inner-city areas the needs of ethnic minorities affect service provision; cultural influences and the need to expose young children to English may override other considerations.

Important considerations here include the following.

- Assessment can be but rarely is streamlined. For example, parents of children with speech and language problems may have to attend for a hearing test, a paediatric examination, a speech therapist assessment and a psychological assessment, all on different days and at different venues. A triage approach by experienced speech and language therapists can dramatically reduce waiting lists and identify those children who have a serious problem.
- There is overlap between health and educational services for assessment of educational problems, such as difficulty in learning to read or spell. In some districts such referrals are passed back to the educational psychologist unless there are additional problems (e.g. school refusal, depression, organic deterioration, etc.), but in many places there is no coherent policy.
- Speech and language therapy should not focus solely on one-to-one treatment but should develop a consultative and advisory service, helping parents, nursery and teaching staff to understand the process of language development. Indeed, accumulating evidence suggests that teaching staff about language promotion and pre-literacy skills, as in some Sure-Start programmes, could be a highly cost-effective use of therapists' time.

The constraints on a good or ideal service include the following:

- lack of clear management structure or lines of accountability in a service involving many disciplines and sometimes several trusts
- failure of primary care trusts to define requirements or commission services
- inadequate investment in staff training
- lack of flexibility with regard to methods of service delivery, priorities and boundaries between professions
- lack of clearly articulated objectives of the service as a whole and for each child, making audit impossible
- failure to use knowledge and services that are already available
- difficulty in liaison with senior officers in social services or education
- little opportunity for clinicians to influence overall policy or budgets.

Mild and moderate psychological disorders

A tiered model for dealing with child and adolescent mental health problems, including mild and moderate psychological pathology, psychiatric disorder and mental illness, has been endorsed by a number of bodies, especially the Department of Health and the Health Advisory Service, the latter developing it in detail in the publication *Together We Stand.*[135] It derives from an earlier paper by Hill for a Royal College of Psychiatrists conference.[136] This format is now a recommendation from the Departments of Health and Education as well as the Social Services Inspectorate.[137] It can be realised within the health service as a Child and Adolescent Mental Health Service (CAMHS), and the principle can be further extended across other agencies. Thus there can be an *inter-agency CAMHS*, a child and adolescent mental health service within the NHS including mental health professionals, paediatricians, school nurses and the primary health care team (*health CAMHS*), and a *specialist CAMHS* comprising the upper three tiers and consisting of child and adolescent mental health professionals.[138] This form of organisation has not been scientifically evaluated but came into being as a way of integrating with other agencies and avoiding duplication of clinical work.

Within the recommended framework there is a series of tiers intended to group together services appropriate for clinical problems with different levels of severity. Within the NHS:

- tier 1 is primary health care
- tier 2 consists of child and adolescent mental health professionals working alone
- tier 3 consists of multi-disciplinary teams, most obvious in child and adolescent psychiatric (child guidance, child and family consultation) clinics
- tier 4 comprises highly specialised provision such as child or adolescent psychiatric inpatient units or tertiary referral clinics for rare problems.

Community child health interventions for mild and moderate psychopathology will be linked to tiers 1 and 2. The model does not accommodate community paediatricians straightforwardly. It will depend upon their personal expertise as to whether they are regarded as child mental health professionals working solo and receiving referrals from tier 1 services (as in enuresis clinics or some ADHD screening clinics) or whether they are the first point of contact with NHS services for some children and families with a mental health problem and thus tier 1.

The mental health contributions of health visitors and school nurses are most likely to be in tier 1.

It is generally supposed that tier 1 services will see the largest number of child mental health problems of all tiers and will also be the focus for much preventative work. Nevertheless, the evidence is that outreach from specialist CAMHS into tier 1 to support and train non-mental health professionals is low (only 1% of specialist CAMHS staff time in the Audit Commission survey).[38]

The child mental health worker concept promoted in the first edition of this chapter has been taken up by a number of services, so that some 60% of specialist community CAMHS employ staff with this remit (sometimes given other titles, such as ‘mental health practitioners’), most from a nursing background. They typically operate at the interface between tiers 1 and 2. Some have been employed to work in close association with general practice, others from a clinic base.

Historically, local authorities have provided a number of social workers and educational psychologists to NHS CAMHS, but this has been unusual in recent years as these professionals have been directed to other priorities such as child protection and the assessment of special educational needs. The clinical burden has therefore fallen increasingly upon the NHS.

Services promoting the mental health of children are provided by several different agencies, of which health is one. Inter-agency commissioning and planning are required in certain areas, such as children’s service plans, but are good practice in any case. This can fruitfully extend to joint commissioning or purchasing, though this alone does not guarantee good practice. The interdependence of social factors, parental well-being and competence, and child psychopathology is well recognised.[139]

Linkage between agencies is currently promoted as national policy. In the field of mild and moderate psychopathology, children’s service plans should prove a conduit for joint planning, but this has not yet obviously borne fruit. In parallel, the child protection procedure has developed a model for inter-agency collaboration but the involvement of general practitioners is notoriously patchy. In the face of apparent fragmentation of health services for children generally and strong representations from users, the House of Commons Health Committee advocated a single commissioner for children’s services or the formation of a single provider unit for children.[140]

When services are organised according to the tiered approach recommended by the Department of Health, some re-allocation of resource to ensure a viable tier 2 is likely to be necessary. Tier 1 (primary care in NHS terms) will need support from tier 2 professionals as well as freedom to refer to them.

It is not known what the volume of service required at each NHS tier will be. This will depend upon the support provided or constraints experienced by other agencies.

8 Outcome measures

The aim of the CCHS is to promote health and prevent disease, disability and death. Measuring impact depends primarily on epidemiological trends data from routine health information systems or surveys. The only relevant routinely available information is rates of death and of infectious diseases, both of which have shown an impressive decline in recent years. Collection of other relevant information about child health has been hampered by problems related to definitions of normality and levels of severity of disease and disability. This is true of rates of injury, disability, abuse, emotional and behavioural problems, and speech and language delay. All of these are in turn related to lack of agreement amongst policy makers and health professionals about the goal of the NHS.

If health and disease represent a spectrum with well-being at one end and distress due to disease and disability at the other, it will be necessary to define and measure well-being. Development of instruments to measure positive health in children is still at an early stage and has yet to be used on a population basis in the UK. Measurement of outcomes in child health has therefore been restricted to process and quality of service provision, together with measurement of risk factors for future health problems.

Evaluation of the service quality which depends on measures of parent and patient satisfaction will also go some way to measuring how well the services have met emotional as well as health care needs. Surveys of schoolchildren collect rates of smoking, alcohol and drug misuse, healthy eating and exercise participation. Surveys of parents collect rates of breastfeeding and passive smoking.

Support and advice to social services departments

The desired outcome for primary prevention is a fall in the number of abused children, but most programmes intended to have this effect involve development of a close relationship with families. This can heighten awareness of child protection risks, so that prevention programmes can have a paradoxical effect on notifications – a research dilemma that is well recognised.

The immediate outcome in child protection cases is a decision about registration followed by development of a child protection plan. Outcomes are usually specified in terms of process and quality measures. For treatment services, desired outcomes include improved mental health and psychological adjustment in adult life, but these have been addressed only in research studies.

Support to Local Education Authorities

Currently used measures of process and outcome are derived from the data in Table 8. These are mostly disease based. The school health service currently measures and records children's height at school entry. These data could be useful for monitoring health, but at present the data are little used and their accuracy is doubtful. Collection of routine height, weight and BMI data at school entry has been proposed as part of a public health minimum data set. Alternatively, this could be monitored by sampling the population rather than by measuring all children. Height is a robust measure of health, and the gradient between social groups may reflect other socio-economic gradients. The BMI data would be useful for monitoring the current 'epidemic' of obesity. The cost and value of this exercise need further evaluation.

Outcome measures of the contribution made by the health service in respect of the Education Act have not been developed. Whilst evaluation of outcomes is important to inform the development of future policy, it has been considered more relevant to assess performance in terms of process and quality, e.g. completion of medical evidence within the prescribed time frame. No outcome measures have been published relevant to the support of children with special needs in mainstream schools. Reviews of the benefits and disadvantages of fully integrating children with disabilities in the mainstream system have been published. Many of these relate to the emotional impact on the child and the family. Successful maintenance of the child with a disability in mainstream school to the satisfaction of the school, the child and the family might be a successful outcome. However, sometimes a move to a specialist unit would be in the child's best interests, and should not be regarded as a failure of either the health or education services. Thus there are no simple numerical measures, but quality and event monitoring would support a policy of continuous professional learning and improvement. A disproportionate number of children with Statements of Special Educational Need are excluded from school, and a fall in this number might indicate progress.

With the exception of research projects which have aimed to capture aspects of emotional and mental well-being, outcome measurement of school health promotion programmes has been restricted to the collection of data on adolescent health-related lifestyles, e.g. rates of teenage pregnancy, alcohol and drug use, smoking, exercise participation and healthy eating. Whilst these are important risk factors for future diseases, they are not synonymous with health. It has been argued that further development of school health promotion programmes depends on the development of tools which measure well-being.[141] Educational and social outcomes, such as progress through school, the numbers of children dropping out of school or leaving with no formal qualifications, or the number involved with youth offending teams, might also reflect well-being and mental health.

Organisation of neonatal and pre-school childhood screening, immunisation and health education programmes

Monitoring of the outcome of screening programmes will undergo development over the next few years as a result of Government policy. At district level, outcomes are likely to be restricted to measures of performance such as uptake, timeliness, referral rate and false-positive rates. The importance of demonstrating that identification in screening programmes has a positive impact on health overall has been stressed in the literature on screening,[142] but measurement of such outcomes requires research projects and cannot be undertaken on a routine basis.

Immunisation uptake rates are reported each year by immunisation co-ordinators, and the incidence of infectious diseases by consultants in communicable disease control. Districts may be required to report on their performance with regard to TB contact tracing and hepatitis B programme coverage. It has been recommended that breastfeeding rates are monitored regularly, together with passive smoking rates.

Whilst the numbers are too small to demonstrate the effectiveness of the programme at district level, trends in sudden infant death demonstrate the effectiveness of the Back to Sleep campaign at national level. Monitoring of aspects of pre-school children's dietary intake has been undertaken in national surveys, but because of the expense involved is unlikely to be practicable at district level. Some districts are experimenting with developing valid measures of the rates of injury from Accident and Emergency registers.

Organisation and provision of health promotion and preventive services which aim to change the micro-environment and child public health services which aim to influence the macro-environment

The outcome of these services is an improvement in the health of parents and children, and their impact is made primarily though improvement in emotional well-being. Until measures which capture these aspects of health are developed, the outcome can only be measured using disease-specific measures (e.g. emotional and behavioural problems, postnatal depression, speech and language delay, incidence of abuse, postnatal depression). All of these outcomes suffer from problems of definition (*see* above). Since it is such an important risk factor for disease and disability in childhood, the level of income differential in families at either end of the social spectrum would be an important outcome measure of child health advocacy. This may in turn be reflected in class-related outcomes, which currently show marked gradients for injuries, birth weight and height at age five.

Children with a disability

For children with *high-severity*, *low-prevalence* disabilities, outcome measures which describe changes in their functional ability can rarely be used in routine practice. The most useful outcome measures for local use address service quality, issues of adaptation and participation for the child, and help for the family to deal with their problems and minimise disruption to their lives.

Success in achieving these aims can be assessed:

- by setting up quality standards (for example, *see* Appendix 2)
- by carrying out an interview or questionnaire-based audit to determine consumer satisfaction (although this is difficult and time consuming, it can be a useful way of taking stock of service quality; standardised instruments are preferable[143])
- by assessing coverage, using multiple data sources (health including primary care, voluntary sector, education, social services) to determine how many of the disabled children in a district use the facilities and services available.

Outcome measures also present difficulties when considering *low-severity*, *high-prevalence* conditions, but process measures describing uptake and attendance, duration of intervention, involvement of carers, effectiveness of triage to ensure optimal use of services and change achieved within each individual child are widely used.

Mild and moderate psychological disorders

The group of problems associated with mild and moderate psychopathology is heterogeneous. Three possible approaches suggest themselves.

- Using a symptomatic rating scale such as the Conners CRS-R.[144] This provides a count of symptoms (complaints by the child and concerns or complaints about them) and some measure of the severity of each individual symptom. However, like many of the rating scales available in the field of child and adolescent mental health, the CRS-R has been designed to focus on psychiatric disorder of greater severity than the mild and moderate psychopathology discussed here. Floor effects are thus likely. Other rating scales such as the CBCL or the SDQ are primarily designed to identify probable caseness in epidemiological prevalence work rather than to detect change, and are likely to be insensitive when used to measure outcome. There is no rating scale which can be generally recommended to detect change related to health care interventions in the field of mild to moderate psychopathology.
- Identifying target problems on an individual basis with the child and parents, and subsequently assessing the impact of an intervention in terms of a Likert scale with agreed anchor points of differing severity.[145] This is labour-intensive, and aims or end-points are likely to vary from one family to another. Nevertheless, it is generally applicable although the reliability between raters in different

domains (general practice, classroom, parent, child, health professional) is low (Hill P, unpublished data). There is no ceiling effect. The implication behind such an approach is that health services are acting as a problem-solving agency. It can be used to obtain a rating from a referrer when the aim of the referral has been solely to provide assessment or consultation to another agency.

- Taking a measure of psychosocial functioning independent of the key clinical problem and assessing the child's functioning on the former. The major instrument for such an approach has been the C-GAS, which requires an assessing professional to allocate a score between 0 and 100 according to a range of suggested anchor points, 100 representing optimal functioning.[146] It is very American in its use of language, and preliminary informal trials have not revealed it to be very popular with UK clinicians. With mild and moderate problems there is the problem of ceiling effects. Nevertheless, it emphasises that services may act to promote mental health as well as solve clinical problems. A UK version, probably simpler in form, would be very welcome.

Assessing outcomes on a large scale is difficult because of the frequent plurality of problems in any one child and the difference in impact of a particular problem in a particular family. There is also the importance of context (facilitative, uninvolved or even opposed parents, schools or other agencies), so that one agency can undermine or amplify work carried out by another. Sometimes the role of services is to slow or arrest decline in functioning rather than restore a symptom-free state. The targets of health service intervention and their mutual priorities are likely to vary between stakeholders. These themes are developed in the paper by Berger *et al.*, reprinted in *Together We Stand*.[135]

Targets

It follows from the above that appropriate targets for the CCHS have yet to be developed and that the service relies on measures which are flawed. For example, falls in the numbers of children on the Child Protection Register could be detected locally or nationally, but are more likely to reflect changes in registration policy than real changes in child care. The same applies to adopted and looked after children. Meanwhile, targets should be set in terms of service quality, coverage and outcomes. High quality of service is best achieved by supporting health professionals, providing regular in-service training and professional development programmes, and supporting those who are caring for very distressed families. It could be argued that the well-being of health professionals who provide these services should be monitored and targeted if found to be poor.

9 Information

The outcomes set out in the previous section suggest the content of a minimum data set to be collected in each district. A core data set of information considered to be of public health importance based on the NHS number has been proposed by the Child Health Informatics Consortium.[147] There would be substantial benefits in a collaborative approach to data handling between health, social services and education, but there are still many obstacles to achieving this. Information on child health inequalities is particularly important, and ways of measuring this are currently under investigation.

Some potentially useful information may be obtained by collaboration with other services. For example, information about the educational and behavioural difficulties in children could be obtained, as from

September 1998, from school entrant baseline testing data. This is collected as a statutory requirement so that the 'value added' offered by each school can be calculated when the next assessment is carried out at the age of seven.[148] Education authorities should be able to provide this data (at least in amalgamated and anonymised format) to the PCT, and this provides useful information about the effectiveness of both the earlier identification and early intervention procedures available for pre-school children. One possible indicator of a successful health-promoting school would be a fall in the number of children out of school, since children who drop out for whatever reason are at high risk of both health problems and educational failure. Early intervention where children are failing in school, or showing a declining attendance record, might if carried out in collaboration with the primary care team have measurable benefits.

Information on the uptake of immunisation is usually reliable for the immunisations given in the first few months of life, but is probably much less reliable for BCG and hepatitis B vaccine. Although the size of the problem for these is very much smaller, high standards are equally important.

Information about child health surveillance uptake is usually collected by general practitioners and health visitors, using carbon copies of standard record pages placed within the personal child health record. These data are collected and aggregated at district level on Child Health Systems which vary from one place to another. Whilst the establishment of these systems is critical for scheduling appointments and chasing up defaulters, lack of epidemiological expertise in the CCHS has meant that many of these data are of dubious quality and underused. Much of the data is potentially of value, and some that might be useful are not currently available, e.g. duration of breastfeeding, depression, injuries, accidents, disabilities or other important health problems.

The principles of risk management should be considered. Although community services are less vulnerable to expensive litigation than departments like obstetrics and orthopaedics, there are nevertheless a number of poorly recognised hazards, and the identification of these highlights areas where quality can be measured.

In order to facilitate comparisons between districts, a list of all child development teams in the UK has been compiled and is available for comparative studies.[149]

A list or register of children with disabilities is kept in most districts but is of variable quality and accessibility. It may be developed in collaboration with educational and/or social services (who are required by the Children Act to maintain a register), though issues of consent and confidentiality increasingly present problems for staff in all agencies. The register records how many children have been seen each year with each diagnostic category, how many with differing levels of disability, and which children are due for review. However, the lack of any nationally agreed system is an obstacle to rational recording and to comparative research, and this needs to be addressed. A list of all equipment and aids supplied (or denied) and of collaborative funding of special school placements and respite care is needed to facilitate budget setting and review.

Many child mental health services have information systems that are downward extensions of adult mental health systems and prove quite inadequate. Correspondingly, paediatric services often have relatively few categories available for psychological problems. Neither derivative is satisfactory. A unified information system is needed which is sensitive to the issues and practice relevant to mild and moderate psychological pathology. The one drawn up by the Association for Child Psychology and Psychiatry[150] has been used in several computerised data sets but has been found to be time-consuming if implemented in full. A common problem is that the data requested by purchasers, provider unit managers and clinicians have not often overlapped, so that a cumbersome total set is the result. Local economy of data entry through the establishment of an agreed minimum set would be appropriate.

10 Research requirements

Most experimental child health promotion research has been carried out in the USA and there is an urgent need for investment in this type of research in the UK. The development of reliable and valid measures of health which capture social, mental and emotional well-being may be a rate-limiting step in health promotion research both for schoolchildren and for parents and children in the pre-school period. Measures are needed which can be collected in self-completion questionnaires for use in trials. Primary health care teams also need a method of data collection to assess their own effectiveness with each individual client. This would be a useful addition to formal randomised trials the results of which are not easy to generalise to everyday practice. Important topics include promotion of mental health, supporting breastfeeding, helping parents to stop smoking, and promoting optimum child development, particularly with regard to language development and behaviour.

More research is needed into the optimum configuration of the health promotion components of the CCHS, including the relative merits of population and high-risk approaches, group approaches vs. one-to-one support and the most efficient use of health professionals and lay staff. The WHO has concluded that RCTs may be inappropriate, misleading and unnecessarily expensive in the evaluation of health promotion interventions.[151] Health promotion research needs investment in units with critical mass and long-term secure funding.

Legislation and central directives may have limited the scope for research on different models of care in some aspects of the CCHS, and arguably as a result may have limited the development of effective services. Policy makers may need to take this potential side-effect into account and draft legislation which enables rather than inhibits research and development. There is a need to research and develop services for secondary and tertiary prevention for child abuse. There is also a need to research the health benefits of the medical contribution to the 'Statementing' of children with special educational needs.

In areas where pre-school health care is poor, or where there are large numbers of newly arrived immigrant or refugee children, the abandonment of routine school-entrant examination might have adverse effects on the health of children. This proposition needs to be examined further with some urgency. It is vital to study not only the number of referrals initiated, but also the extent to which the cases identified have conditions that were not previously suspected, are significant for the individual, and are susceptible to treatment or intervention. Although there is an extensive research literature, there is still much controversy about a number of screening issues in child health, particularly the value of pre-school and school vision screening, hearing and height screening at school entry, and screening for congenital dislocation of the hip and congenital heart disease in infancy. The health benefits of these programmes warrant further research. For rare conditions, a national register would be a valuable aid to research.

Children with a disability

Proposals for research in the field of childhood disability are summarised in Box 10.

Box 10: Research needs in the field of childhood disability.

Basic neuroscience and genetics research	• Inheritance, environment and brain mechanisms in learning disability, autism, speech and language disorders, hearing loss, cerebral palsy, etc.
Clinical research	• Outcome measures and outcomes for therapy services • Effectiveness and cost-effectiveness of new therapies • Role and impact of non-orthodox therapies
Health services research	• Definitions of disability – coding systems and database organisation • Measures of the quality of life for disabled children • Reasons for variability in service provision for disabled children • Optimum staffing levels for child development teams • Relationship between secondary and tertiary disability services • Delivering the service standard set out in the Charter (*see* Appendix 2) – obstacles and costs

Children with mild and moderate psychological disorders

It has been asserted that the major difficulty in this field (as in child and adolescent psychiatric disorder) is the poor level of co-ordination between agencies relevant to child and adolescent mental health, both within the NHS (child psychiatry, child psychology, hospital and community paediatrics, adult psychiatry and primary care) and across health, education, social services, youth justice and the voluntary sector.[152] A number of new Government initiatives are promoting and will promote inter-agency linkage and need evaluative monitoring. The tiered approach provides a potential answer to some of these problems, but its interpretation varies and a comparative evaluation of approaches based on tiered models is required. This might be qualitative in the first instance, and for mild and moderate psychopathology might address the ways of working of tiers 1 and 2 in particular, across NHS specialties and agencies.

The use of problem resolution as a target measure is hampered by comorbidity and Likert scaling, and is confused by differences between raters according to which domain the child is in (school, home, peers, etc.). The development of a children's scale of adaptive functioning which is less complex and less Americanised than the C-GAS (*see* 'Models of care – Mild and moderate psychological disorders' above) is needed.

Appendix 1: Working with non-government organisations in the voluntary or charitable sector

Provision of services

- Mother and toddler groups.
- Drop-in centres for parents with young children.
- Bereavement support: one-to-one and in groups.
- Support for parents of children with a disability.
- Home visiting and befriending.
- Group-based parenting programmes.
- Health visitor, midwife and teacher training.

Benefits of NHS collaboration with voluntary sector

- Services do not suffer from the stigmatisation attached to clinical or social service provision.
- Providers have credibility because of their experience as parents, and can offer practical information and advice on how to cope in a way that may not be easy for professionals.
- Services are in tune with what the consumers want.
- Groups of parents in voluntary organisations are better placed to develop a genuine partnership with professionals.
- Access is allowed to information and insight which otherwise would not be available to professionals.
- Work experience is provided for mothers returning to work, giving them experience and confidence.
- Non-professional services are less expensive than professional services, but the cost of recruiting, vetting and training volunteers can be significant.

Limitations

- Volunteers and voluntary groups are not representative of all children or all shades of opinion.
- Voluntary work can become a crusade or a way for an individual to deal with their own problems.
- Recruitment difficulties – many people undertake voluntary work for a short period of time in order to gain experience and confidence before seeking to re-enter the world of work.
- The cost of recruiting, vetting and training volunteers can be substantial.
- Professionals are often anxious about aspects such as skill, confidentiality and commitment.
- It is difficult for professionals to keep up to date with all the different voluntary groups which may exist in the locality.
- Variations in the number of volunteers available to provide a particular service may mean that some referrals are not taken up, making it less likely that the professionals will make use of the organisation again in the future.

Insecure funding available to voluntary groups – and variation in numbers of volunteers – means that service provision can be erratic. (More permanent financial support would undoubtedly make them more efficient and effective. Often this is a preferable option to providing short-term start-up funding to new organisations.)

Appendix 2: A charter for disabled children and their families

Principles

- The family should feel that they have been listened to and heard, and that their concerns and aspirations have been taken seriously, and that their responsibility to their child is respected.

Referral and follow-up

- There should be a prompt response to the first referral (within one week), and the degree of urgency and parental anxiety should be considered when arranging the first appointment.
- The child should receive either regular medical follow-up or open access to the consultant in the event of new problems.
- There should be arrangements for children with complex medical needs to be seen urgently on request. The family should know whom to contact in the event of new problems.

The diagnosis and the disability

- The process of ‘news-breaking’ should follow established guidelines, whichever professional undertakes the task. Where necessary, training should be provided. There should be arrangements for an early follow-up appointment and/or home visit, and telephone support should be available.
- The parents and child should know the correct name, label or description for the child’s condition, and its prognosis and functional implications.
- Investigations should be carried out according to current best professional practice. Even if no exact diagnosis can be made, the family should know what tests have been done and what the results mean. If the situation changes, any new investigations should be explained.
- The child’s future needs (e.g. for care in adolescence and adult life, or for terminal care in the case of progressive disease) should be discussed with the parents and the child as soon as possible. There should be planned handover to a relevant, co-ordinated adult service, in line with the requirements of current legislation.

Treatment and therapy

- If the child takes any medication, the parent should know what, why, for how long and how much. They should have a medication card to summarise complex drug or multiple therapy.
- The family should know what sort of therapy or teaching the child is receiving, what it is intended to achieve and how they can help. There should be defined and achievable goals. The parents and child should understand what system of prioritising need is used by therapists and the reasons for any delays in commencing a treatment programme.
- The family should know what other methods might be offered by others for treating the child’s condition (including both orthodox and controversial therapies, and alternative medicine) and why the team/therapists are not using them for the child. They should be aware that some treatments of

dubious efficacy can be disturbing and distressing to children. Families who try other methods should continue to receive support.

Information

- Every family should be offered full information about the child's condition (including implications and prognosis), a meeting with another parent whose child has the same problem, and the name and phone number of the organisation for children with this condition.
- Every family should be offered expert information about the genetic aspects of the child's condition, either by a clinical geneticist or by a well-informed paediatrician. This information should not be omitted even when the condition is thought by the professionals to be non-genetic.

Medical care and support

- The growth of every child should be monitored. Every child should have access to expertise on feeding problems and techniques, and nutritional support.
- Every child should be offered hearing and vision assessments as appropriate.
- Every parent should know about day care (day nurseries, etc.) and respite care (short breaks). There should be a range of respite provision and other relevant local support services.
- Every child should be offered prophylactic dental advice and access to dental specialist services if needed.
- Every parent should know about benefits and the Family Fund.
- Every child with cerebral palsy associated with a risk of hip dislocation and/or scoliosis should receive regular orthopaedic checks and hip and spine X-rays as appropriate.
- Every child should be offered a full immunisation programme unless there are recognised contra-indications.
- Every parent should know about pre-school educational help (home teachers, Portage, etc.), their rights under the Education Act, and the procedures involved with assessment and Statements of Special Educational Need. Limitations in resource provision should be explained. There should be an impartial source of advice on services.
- The family should be provided with all equipment and aids appropriate to the child's needs.
- There should not be undue delays in providing or repairing the equipment. If delay is unavoidable, the family should be kept informed.
- The family should be invited and encouraged to identify other important service needs. They should be able to offer suggestions and there should be a clear complaints procedure.

Appendix 3: Recommended minimum service provision through European countries for children with disability[153]

Philosophy

1 Services should be needs led.
2 Use terms such as 'normalisation' and 'therapy' with care and with adequate explanation.
3 Some services should be available as a basic right and not require validation.

Process

4 Care programmes should be goal orientated and individually adapted.
5 Early identification is the key to early intervention and service availability.
6 Services should be provided by local, well-co-ordinated teams.
7 User input is essential to planning, development and managing services.
8 Appropriate support for behaviour problems should be an integral part of service provision.
9 Disability services must be locally based with ready access to tertiary support.

Structure

10 Children with rare disabling conditions may need considerable tertiary care but should also receive support from a local disability service.
11 Better information on numbers of disabled children and services available is needed at local levels.
12 Integration into mainstream education is to be encouraged where appropriate.
13 Inter-agency collaboration (health, education, social services) is important for providing a comprehensive service.
14 Proper business plans with costings and coverage need to be developed.

Appendix 4: Education Act and Code of Practice

The NHS Act 1977 requires the Secretary of State to provide for the medical and dental inspection of schoolchildren in maintained schools at appropriate intervals, and the Education Reform Act 1988 extended this to include grant-maintained (opt-out) schools. Independent schools should make arrangements with the provider unit ('Child health in the Community'[17] 8:21).

Section 166 of the Education Act 1993 requires health authorities (now PCTs) to comply with requests from Local Education Authorities in respect of children with special educational needs unless, having regard to the resources available to them, it is not reasonable for them to comply with the request.

Negotiating School Health Services and **Nurses and Purchasing: School Nurses in the New Health Service Structure** advise purchasers to consider the pattern of services in schools, paying particular attention to dental care, consent to medical examination, medication in schools, health care needs of children with special needs, independent schools and training.[17]

The Education Act 1993 required the British Secretary of State for Education to publish guidance on good practice for the identification and assessment of children with special educational needs in the Code of Practice, to which all involved must have regard.

The 1993 Education Act developed and extended the **Education Act of 1981**, which in turn was based on the Warnock Report 1978. The 1981 Act had a wide range of recommendations, but the requirement for a formal assessment and the written Statements of Special Educational Need became the prime concern of educational and health services. One of the aims of the 1993 Act was to take note of the lessons learned as a result of experience with the statement process.

Key elements of the 1994 Code of Practice (now superseded by the **Special Educational Needs Code of Practice** 2001; *see* www.dfes.gov.uk/sen/) included the following.

- Early identification of the children who may have special needs and notification to the education service. There should be a named person responsible for liaison with the Local Education Authority.
- Twenty per cent of children may have special educational needs at some point. Identification and intervention have five stages. At stage 1, the teacher reviews the problem with the parents. At stages 2 and 3, advice may be sought from health experts and others. At stages 4 and 5, where formal assessment and written statement, respectively, may take place, health advice is a necessary part of the process.
- The health advice must be submitted within 6 weeks of the request and the formal assessment process must be completed in 26 weeks.
- Annual reviews of children with a Statement of Special Educational Need are statutory. From age 14 onwards there must be a transition plan. The Local Education Authority is required to consult child health services, for the first review after the pupil's 14th birthday and any subsequent annual reviews until the child leaves school. This is good practice for children with disabilities even if they do not have a Statement of Special Educational Need.
- Subsequent legal interpretations of the Code and the law have addressed the problem of providing therapy services such as speech therapy for children with a Statement of Special Educational Need.

In addition, education authorities are encouraged to:

- establish a monitoring group with health and social services
- ensure a named health service contact for each school
- agree a process for specifying and providing equipment (e.g. for seating, mobility and communication)
- have a means of discussing with other agencies pre-school children with special educational needs
- review children placed outside the local authority with involvement of other agencies
- agree a policy on health promotion and sex education for children with special needs.

Appendix 5: The Children Act (1989)

This provides the framework for the care and protection of children. The Act defines children in need as follows.

> *A child shall be taken to be in need if:*
>
> *(a) he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority;*
>
> *(b) his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services;*
>
> *(c) he is disabled.*

(*See Working Together Under the Children Act 1989*. London: HMSO, 1991.)

Child protection

The health authority (now PCT) must:

- comply with requests for help from a local authority
- identify a senior nurse with a health-visiting qualification as designated senior professional to be a member of the Area Child Protection Committee (ACPC)
- take a strategic lead in inter-agency child protection matters
- ensure that service specifications include child protection
- co-ordinate Part 8 reviews of cases where a child has died or suffered serious harm
- identify a designated doctor for child protection.

Trusts must:

- provide training in child protection
- identify a named nurse and doctor for child protection within the trust.

Commissioners (including primary care groups and trusts) must:

- purchase child protection services
- purchase health-visiting services that fully meet child protection aspects of the health authority (now PCT) service specifications.

Appendix 6: Adoption and fostering

The **Adoption Agencies Regulations 1983**[73] state that at least one registered medical practitioner should be nominated to act as Medical Adviser, to be a member of the adoption panel and to be consulted regarding access to and disclosure of health information. The functions of the adoption panel are to recommend whether adoption is in the child's best interests, whether adoptive applicants are suitable and whether applicants are suitable for particular children.

Over 20 000 babies and children were placed for adoption each year in England and Wales in the early 1970s. This has now fallen to less than one-third of that figure. Half of these are placed with step-parents and the other half to a permanent substitute family as a consequence of neglect, rejection, abuse within the biological family or because of disability and handicap. Thus most adopted children are now not straightforward 'normal' children.

The **Arrangements for Placement of Children Regulations 1991** and the **Review of Children's Placements Regulations 1991**[73] set out the requirements for 'medical examinations with written records of every six months for children under two and thereafter every year, with child's consent'.

(The number of children looked after each year is approximately 50 000, but many are very short term: at any one time the figure is approximately 30 000 [100–200 per 100 000 total population].)

The Utting Report[34] made the following recommendations.

- 'Local authorities must pay particular attention to the educational and health needs of children they look after.'
- 'Local authorities must observe the regulations governing the placement and supervision of children in foster care.'
- 'Local and health authorities should assess and meet the need for treatment of children who have been abused.'

Appendix 7: The health-promoting school

There are three main components in health-promoting school programmes:

- health education – a curriculum aimed at providing new knowledge, challenging existing attitudes and developing skills
- health-enhancing changes to the school ethos and environment – developing policies, improving relationships among and between staff and pupils, and ensuring a healthy physical environment
- involving parents and the wider community in health-promoting initiatives.

The criteria for health-promoting schools in England are:

- active promotion of the self-esteem of all pupils by demonstrating that everyone can make a contribution to the life of the school
- development of good relationships between staff and pupils and among pupils in the daily life of the school
- clarification for staff and pupils of the social aims of the school
- provision of stimulating challenges for all pupils from a wide range of activities
- use of every opportunity to improve the physical environment of the school
- development of good links in and between school, home and community
- development of good links among associated primary and secondary schools to plan a coherent health education curriculum
- active promotion of the health and well-being of the school's staff
- consideration of the role of staff as examples in health-related issues
- consideration of the complementary role of school meals (if provided) in the health education curriculum
- realisation of the potential of specialist services in the community for advice and support in health education
- development of the education potential of school health services beyond routine screening and towards active support for the curriculum.

Appendix 8: Role of the immunisation co-ordinator

- Establish and monitor the information and appointments systems; ensure efforts are made to reach ‘difficult’ families.
- Make monthly reports of immunisation statistics.
- Ensure that there is continuing education on the subject of immunisation at local level.
- Form an advisory group with members from other disciplines, including community or public health, nursing, general practice, pharmacy, health promotion, etc.
- Monitor cases and outbreaks of infectious disease in collaboration with the CCDC (consultant in communicable disease control).
- Plan campaigns and programmes for the introduction of new vaccines and for changes in the existing protocol of immunisation.
- Ensure the maintenance of the ‘cold chain’ (i.e. ensuring safe refrigerated transport and storage of delicate vaccines, especially polio vaccine, which is inactivated by heat or sunlight).
- With the CCDC, monitor service provision for BCG, TB contacts and hepatitis B vaccine coverage as well as for the basic vaccine programme.
- Provide advice in cases where doctors and/or parents are doubtful about immunisation or where there are contraindications in a particular case. Many districts provide an immunisation advice clinic.
- Provide training for health visitors to give immunisations themselves. It is useful for health visitors to have this skill, particularly in cases where parents are reluctant to come to clinics.

Appendix 9: Specialist services needed by disabled children

Specialist or service	Examples
Paediatric neurologist: combined clinic, peripatetic service; regional centre for investigations and treatment.	Diagnosis of unusual or obscure neurological disorders causing disability; management of complex epilepsy; botulinum toxin treatment trials, etc.
Clinical genetics: peripatetic or regional centre.	Diagnosis of chromosome disorders, dysmorphic syndromes, genetic counselling. Important whether or not referring clinician thinks child's condition is genetically determined.
Child psychiatry: district service.	Suspected autism, disintegrative psychosis, behavioural problems in disabled child. Referral to specialist centre may be needed for some problems, especially self-injurious behaviour which can be life-threatening.
Clinical psychologist (if not part of CDC team): district service.	Opinion on developmental problems (intellectual assessment, etc.), behaviour problems, parental stress and management problems, family conflict over care of disabled child.
Community mental handicap team (CMHT) (team for people with learning disabilities): district service.	In most districts, children with learning disabilities are cared for by the paediatric services with the support of child psychiatry/psychology; handover to the CMHT may be in the early teens, or at school leaving.
Cardiologist: regional or peripatetic.	Congenital heart defects may be part of range of the child's disabilities.
Orthoptist and ophthalmologist: district, but regional or supra-regional for uncommon conditions.	Eye defects and disorders are more common in children with other disabilities. Complex behavioural problems and developmental setback in blind children need specialised team.
Audiologist: district, but regional or supra-regional for some investigations and for cochlear implant.	A hearing check is vital for all disabled children – multiple impairments are common. Hearing-impaired children need wide range of services.
ENT surgeon: district except for rare or complex problems.	Treatment of glue ear; salivary duct transplantation; laryngeal or tracheal stenosis, especially in prematures.
Paediatric surgeon: supra-district or regional.	Repair of spina bifida, replacement of valves for hydrocephalus, bladder problems, gastrostomies, congenital anomalies.
Paediatric orthopaedic surgeon plus orthotist: supra-district or regional.	Dislocated hips, scoliosis and contractures are common in disabled children. Judgements about surgery are often very complex.
Paediatric neurosurgeon: supra-district or regional.	Spinal problems, e.g. late complications of spina bifida repair. Shunt complications. Congenital anomalies.
Paediatric gastroenterologist and/or surgeon, dietitian, speech therapist: district, but complex disorders clinic supra-district or regional.	Severe feeding and swallowing problems are common in severely physically disabled children; may need tube feeding or gastrostomy. Constipation is common and often intractable.
Dental and orthodontic care: district.	Dental disease is not different in disabled children, but it is harder to assess and treat and many children need specialist expertise.
Wheelchair and seating services: district for most, regional for complex seating.	Some equipment is readily available; a few children need custom-made or specially ordered wheelchairs or seats; bio-engineering service.
Communication aids centres: regional or supra-regional.	Ensure that the correct equipment is purchased, and follow-up must be continued until the child's family and teachers can use it correctly.

Appendix 10: The children's audiology service

Screening and management tiers

- **Level 1 – screening services:** The infant distraction test (IDT) by health visitors; the sweep test used to screen children starting school; neonatal screening.
- **Level 2 – children referred from level 1:** Secondary screening to select children who need a full diagnostic evaluation. May manage children with minor hearing loss, behaviour problems such as inattention, and speech and language impairment; mostly in the 2–4 years age group.
- **Level 3 – full diagnostic and management service:** Hearing-aid provision, syndrome diagnosis, genetic advice, co-ordination of early speech and language therapy, education, psychology, social work, long-term supervision. (*Note*: In some districts, level 2 and level 3 are provided as a combined service.)
- **Level 4 – tertiary services:** Referral for specialised investigation, genetics, cochlear implants, etc.

Changes proposed in the near future

- **Move to universal neonatal screening:** The IDT produces disappointing results; universal neonatal screening is a better investment. If implemented, this would substantially reduce the volume of work at level 2. The cost of neonatal screening is less than the true cost of the health visitor test, and the yield is greater.
- **Standard of service:** Neonatal screening presents a variety of new challenges, and guidelines for a 'Family-Friendly Hearing Service' are being prepared (MRC Institute of Hearing Research, University of Nottingham). Districts will need audiological scientists, technicians and managerial/public health expertise to maintain a high standard of neonatal screening and follow-up. Full evaluation, including genetic studies, for the underlying cause of hearing loss is also vital.
- **Review service for 2–4 years age group:** Experienced speech therapists run triage to sort these referrals, and it is suggested that they could in addition undertake first-level audiology screening and basic psychological assessment.
- **Review school-entrant testing:** The sweep test at school entry detects a large number of children with middle ear disease, but the value of this exercise and the best referral pathway are under scrutiny.

Appendix 11: What primary health care teams could do to improve services for adolescents in primary care and community settings: general principles

- Create a practice profile for 10–18-year-olds using the age/sex register.
- Provide positive information stressing confidentiality (posters, leaflets, reassurance during face-to-face consultation), and confirm that this applies to every member of the practice or clinic.
- Create an environment that is user-friendly to adolescents. This includes the attitudes of staff as well as the physical environment.
- Make sure that teenagers know about the services on offer by publicity through schools, school health staff, or by arranging for teenagers to visit the clinic or health care facility as part of a school personal development programme.
- As children approach puberty, educate parents about the need for children progressively to take responsibility for their own health and health care and encourage them to consult the doctor on their own.
- Offer the freedom to change GPs when a person reaches the age of 16.
- Make use of routine health care opportunities such as immunisation, minor consultations for health problems, or invited routine health checks.
- Provide specific information for parents about health problems of the teenage years.
- Since few doctors have any specific training in communication skills with adolescents, this must be included in GPs' and paediatricians' training programmes and also incorporated in undergraduate teaching.

Appendix 12: Philosophical models of service for disabled children[130]

The expert model

The professionals give information. They inform the parents of the results of the assessment. They assess and treat the child:

- according to their own perceptions
- with minimal negotiation of goals with parents or other carers
- in a place of their choosing.

The expert model is outmoded. It does not allow for the differences between families, nor does it consider the need to relate professional goals to family needs and priorities.

The transplant model

The professionals provide the expertise and teach the parents to carry out particular tasks. In this model it is implicitly assumed that:

- parents know their own child better than anyone else can
- parents are motivated to help their child
- parents have the personal resources to carry out what is required of them
- the professionals will be in charge of the management plan
- the professionals have the ability to communicate the necessary skills to the parents.

The transplant model maintains the dependent role of the family in relation to professional services. It does not address the problem of multiple professional inputs.

The consumer rights model

This model emphasises the parents as consumers and assumes that:

- parents have the right to select services and interventions that they feel are appropriate
- parents will need information in order to make these choices
- parents have the expertise to judge for themselves what is needed in the light of their life situation.

It follows that:

- service packages would need to be tailored to individual family needs
- sometimes the family and the professionals would have different perceptions of the services needed; if this happened, the parents' views would be respected
- negotiation about service provision would be essential
- parents would be part of the management structure of special needs services.

The danger of this model is (in theory at least) that it neglects the child's needs in favour of those of the whole family.

The social network model

This model emphasises the child as a member of a social network and assumes that:

- environmental factors interact with biological disadvantage in complex ways
- under most circumstances, the child's social network is a more powerful factor in influencing development than any professional service
- families may rate factors causing social disadvantage (poor housing, unemployment) as more important than developmental problems
- parents will draw on their social networks for information, ideas and support as much as, or more than, their professional advisers
- families previously labelled as 'difficult' or 'non-compliant' would be regarded as having different priorities
- professional skills would be used to assist the family in setting, adjusting and achieving its priorities for the child.

The empowerment model

This combines features of the consumer rights model and the social network model.

- It emphasises the empowerment of parents, i.e. the aim is to facilitate the parents' ability to make and carry out decisions and actions which they consider to be right for them.
- It aims to build on the strengths of the family rather than its weaknesses.
- It retains the professional role and responsibility to consider the needs of the child and to help parents to consider how these can be met.
- It has implications for the ways in which services are provided and monitored.

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Addendum

Since this chapter was completed, there have been a number of important developments. Of these, the most significant is the publication in April 2003 of the first section of the National Service Framework (NSF) for Children, on acute and hospital services, together with an overview of preliminary proposals regarding other aspects of child health including those covered in this chapter, under the title 'Emerging findings'. These can be obtained via the Department of Health website. The remainder of the NSF is expected to be published in the spring of 2004. Other relevant reports and documents are summarised below.

In January 2003, the fourth edition of *Health For All Children* was published (Oxford: Oxford University Press). This replaces the third edition. It further emphasises the move towards health promotion and community development and expands on several emerging issues such as parent education, parental mental health and substance abuse. There are some revisions to the programme of child health surveillance, setting out various options in anticipation of the NSF. The screening topics are updated in the light of work by the National Screening Committee.

Several Government programmes have continued to grow in size and importance, including Sure Start, Connexions and the Children's Fund. Further details can be obtained from the websites for the DfES and the Children and Young People's Unit, respectively. The Government also published an overarching strategy, *Tomorrow's Future*, in 2001.

The report by Lord Laming on the Victoria Climbié case in 2003 has highlighted the need to improve child protection procedures, and new initiatives are expected soon, including legislation that will be based on the proposals in the Green Paper published in response to Lord Laming's report (*see Keeping Children Safe* and *Every Child Matters*) (www.dfee.gov.uk/cypu); *see also Safeguarding Children*, 2002).

In 2003, the Audit Commission published a review of *Services for Disabled Children* with wide-ranging recommendations for improvements (*see* www.audit-commission.gov.uk).

In 2002, the Royal College of Paediatrics and Child Health published a review entitled *Strengthening the Care of Children in the Community* (*see* www.rcpch.ac.uk).