

Babies behind bars revisited

D Black, H Payne, R Lansdown, A Gregoire

Mother and baby units in prisons in the UK, 2004

The UK has the highest rate of female imprisonment in the European Union as at March 2004, and the steepest rate of increase.¹ It was estimated in March 2003 that 32 000 children per year (age under 16 years) are separated from their mother due to her imprisonment,² a figure which includes 2880 children under 18 months of age. There is currently a facility for only 90 children under 18 months old to remain with their mother in prison at present in England and Wales, although by spring 2005 the capacity will have increased to 114.³ The budget for the Prison Medical Service was transferred to the NHS from the Home Office on 1 April 2003 with a plan to transfer service delivery and management by 2008.⁴ As this offers an opportunity to reconfigure commissioning and services for children (approximately 0.2% of the child population of the UK) affected by maternal imprisonment, especially children who may suffer from being separated from their imprisoned mothers, we wish to initiate a discussion among colleagues in paediatrics, general psychiatry, child psychiatry, and psychology, regarding issues pertaining to children with imprisoned mothers. We wish to revisit the review of "babies behind bars" of 1992⁵ and explore the statistical trends, demographic influences, and service implications, and examine the implications of set age limits for the residence of children in prison mother and baby units (MBUs).⁶

IMPRISONED MOTHERS IN ENGLAND AND WALES

The number of women remanded in custody or receiving custodial sentences in England and Wales is increasing. In 1993 the point prevalence of women in prison was 1580, and in March 2004 it was 4589, an increase of nearly 300% in 11 years,⁷ and the highest rate in the European Union as it stood at March 2004. The much higher current male prison population (nearly 70 000) rose by less than 30% over the same period.

Two thirds of women in prison are mothers of children under the age of 16 years.⁸ The majority of the mothers are aged 18–34 (87%) and on average each woman has 2.1 children, 30% of the

children being under 5 years of age. During 2001 (the most recent year of full published statistics), 15 876 women were imprisoned, who were mothers of 31 752 children. The most recent research from 1997⁹ suggests that three quarters of the children were living with their mother before the offence for which she was imprisoned, and most of these children (85%) had never been separated from their mother before her incarceration. Half of all women prisoners are held at least 50 miles from home, and a quarter are more than 100 miles away, with the result that only half of mothers are visited by their children in prison.

OFFENCES AND SENTENCES

Only 31% of women remanded in custody receive a custodial sentence, although courts are increasingly likely to use custodial penalties for women⁷ (men are still much more likely to receive custodial sentences). Of all convicted women receiving a custodial sentence (15 876 women during 2001), 61% (9684 in 2001) received a sentence of less than six months; 18% (2858 in 2001) were sentenced to between 7 and 59 months, and 21% (3334 in 2001) received a sentence of 5 years or more. Over one third of the women were convicted of drug offences (compared to 15% of male prisoners), and 30% of these women were foreign nationals⁸ being used as "drug mules"; that is, pregnant women sent by drug barons to smuggle drugs in the belief that pregnancy makes a woman less likely to be detected. These women receive long, deterrent sentences (up to 10 years) and usually have no relatives or friends in this country who can look after their children, when born.

PRISON MOTHER AND BABY UNITS IN ENGLAND AND WALES

For over 100 years in the UK, mothers have been allowed to keep their babies with them in prison, but no formal arrangements were made until the early 1980s.⁶ At present in the UK there are five women's prisons with mother and baby units (one in an open and four in closed prisons), and two more are due to open³ (see table 1). There is current

capacity for 90 children, and by 2005 there will be capacity for 114. Despite this increase it is possible that with the rising prison population a child under 18 months of age could be separated from its imprisoned mother purely due to a lack of capacity in mother and baby units. This could be in direct contravention of the child's right to family life under Article 8 of the Human Rights Act (HRA) 1998,¹⁰ although the limitations of the HRA would need to be determined by a court.

REVIEW COMMITTEE RECOMMENDATIONS 1999

A Review Committee of the Prison Service 1999 regarding young children in prison with their mothers made over 60 recommendations.⁶ The stated overarching principle is that "the best interest of the child is the primary consideration", although because of conflicting issues such as prison discipline, the interest of the child is not expressly paramount. The report recommended that the Prison Service take responsibility for child protection and other responsibilities with regard to child development and general well-being relating to recent UK legislation.¹¹ It also recommended that planning for the child's departure from prison (in ideal circumstances, at the same time as the mother) should start on admission, and, if the mother's sentence was a long one, the child should stay in only long enough to be breast fed and/or for other arrangements to be made for long term care.

Most (46) of the 62 recommendations were accepted by the Prison Service,¹² including the increase in provision of MBU places, application and admission, child care planning and reviews, drug free conditions, crèche facilities, parenting support, and family and community contact. Relevant prison staff undertake specialist training, and there must be a designated Mother and Baby Liaison Officer (Prison or Probation Officer) in all women's prisons. A further 11 recommendations were identified "for further consideration" and four were rejected.

PLANNING ADMISSION TO AN MBU

All remanded and imprisoned women who are pregnant or mothers of children under 18 months old are entitled to apply for a place at an MBU. The designated MBU liaison officer at each women's prison has the duty of making eligible inmates aware of MBU facilities.¹³ An application from a mother is considered at an admissions board with an independent chair, which receives reports from probation, social services,

Table 1 Current profile of mother and baby units

Prison	Prisoner status	Security category	Places	Upper age limit
HM Prison Service mother and baby units				
Askham Grange, near York	Sentenced	Open	30 mothers 33 babies (accommodation for twins)	18 months
Holloway, London	Remand and sentenced	Closed	17 mothers and babies	9 months
New Hall, near Wakefield	Remand and sentenced	Closed	9 mothers 10 babies (accommodation for twins)	9 months
Styal, Cheshire	Remand and sentenced	Closed	22 mothers and babies	18 months
Eastwood Park, Bristol	Remand and sentenced	Closed	12 mothers and 13 babies.	18 months
Bronzefield, Ashford	Remand and sentenced	Closed	12 mothers and babies	18 months
Due to commence 2005				
Peterborough	Opening March 2005	Closed	12 mothers and babies	18 months

There are currently 90 mother (95 baby) places in total spread between five prisons.
Total projected capacity by 2005 = 114.

and the woman's current prison, and makes a recommendation based on the best interests of the child, but also taking into account the length of the mother's sentence and whether there is a vacancy. The prison governor makes the final decision, although the mother has a right of appeal to the Head of the Women's Estate. The woman must be drug free and agree to stay off drugs, with the exception of a methadone withdrawal programme. The mother must agree to be of good behaviour and must be able to look after the baby herself.

PRISON POLICY AND QUALITY OF LIFE FOR THE CHILD ON THE MBU

It is policy for imprisoned pregnant women to be transferred to hospital to give birth (to ensure appropriate medical care and to avoid place of birth on the birth certificate being a prison).^{14 15} On the MBU, to avoid children being locked in cells, the mother must agree to remain voluntarily in the cell for the required periods (cooperation is a prerequisite for admission and continuation at the MBU). MBUs are segregated from other areas of the prison, with washing and cooking facilities and play areas so that normal activities of daily living can be pursued between mother and child. The mother agrees to remain drug free. Crèche facilities are provided during the day so that the mother may work or attend education or other courses designed to reduce future re-offending behaviour. Breast feeding is encouraged as is appropriate child care, feeding, hygiene, interaction, and play. Healthy eating, non-smoking, and visits from the Health Visitor are promoted. The child may leave the prison (be taken out for day care) if this is arranged locally, to give the child as much opportunity as possible for a normal range of interactions and community experiences. Women's prisons may have more relaxed and extended visiting than other prisons. Regulations promote and

finance visits by Looked After children to their mothers in prison, and mothers may have three-monthly home visits to see children. However, the 2001 Inspection Review identified that a number of significant areas affecting child visiting were still not fully achieved in many prisons, including family visiting facilities, day visits for children, family contact development officers, and a reduction in the four week waiting time that a woman must wait before assessment for eligibility for a child visit.¹⁴

DISCHARGE FROM THE MBU

Ideally, the child would leave the MBU at the same time as the mother, at the end of sentence, thus avoiding the trauma of separation. Discharge planning is an intrinsic part of the admission decision,¹² and there may be some situations where separation is better performed early than late. If the mother has a long sentence, the inevitable separation at around the age of 18 months when the child has to leave prison, may be more traumatic for the child than separation around the time of birth and placement in foster care with regular contact visits to the mother in prison. Three recent judicial decisions inform this subject. A recent judgement¹⁶ held that before a young baby can be separated from its prisoner mother, the decision maker must consider the baby's right to respect for his family life, and determine whether such interference with such right is proportionate. This followed the case of a child, AD, who was excluded from an MBU following the mother's misbehaviour and was placed by the mother in the care of a friend (a former prisoner, who looked after the child in an exemplary fashion). At the time, AD was still being breast fed by CD. The court held that no proper consideration had been given as to whether the separation was in AD's best interests. Despite the quashing of

the exclusion order from the MBU, mother and baby were not reunited.

In another case, the mother appealed to allow her child to stay longer than 18 months, as her child was displaying separation anxiety. Judicial Review¹⁷ held that the Prison Service had the right to determine when a child should leave a prison MBU, but should exercise flexibility about the upper age limit rather than operating a strict policy of separating the child from the mother at 18 months of age. The most recent case¹⁸ confirms that the best interests of the child require early permanency planning on entry to the MBU, and that early separation may be reasonable in the light of present knowledge.

DISCUSSION

It can be anticipated that 18 months might be the most difficult age for a child to separate from its primary carer, but what, if any, would be an appropriate change to the current upper limit? The Review Committee⁶ decided to make no recommendations for change as it felt that any changes proposed should be evidence based. The limited research is inconclusive. The only major study of the development of children of imprisoned mothers¹⁹ showed no evidence of severe and general effects on babies due to either prison institutionalisation or separation from the imprisoned mother. The author's commentary suggested that the outcome for the child depended on a range of factors, including the substitute care offered, and the initial mother-child relationship. Caddle gives examples from other countries of alternatives to MBU provision, including occasional residential stays with mother in prison for older children, three weeks' leave per year for mothers, delayed custody, or community sentences.²⁰ The Review Committee recommended that further research was urgently needed to establish the experience of children in MBUs,

any possible optimum upper age limit for a child to be resident, and to determine what the implications were for older children of remaining in a prison environment. The Director-General asked the Women's Policy Unit of HM Prison Service in 2000 to assess the feasibility of a pilot study at HMP Ashkam Grange MBU to explore the possibility of increasing the upper age limit. The Prison Service reports that the "assessment concluded that there were serious ethical difficulties in the proposal and a high financial cost and that the first priority should be to improve the assessment processes in MBUs".

Clearly, a sound evidence base for this decision about the upper age limit is urgently needed. In the meantime, while empirical evidence is awaited, there is a need for professionals to debate the issue from the theoretical standpoints of attachment, separation, and substitute care. Is it better for a child to live with the mother in prison, and visit the community, or live in the community with family, friends, or foster carers and visit the mother in prison? If separation must occur, what is the least damaging age?

From the point of health care service delivery in the UK, professionals have a window of opportunity to influence the future shape of health services for prisons, during this period of transfer of services to the NHS.

The Royal College of Paediatrics and Child Health (RCPCH) should take a lead in the UK and engage Child and Adolescent Mental Health Services (CAMHS), General Practice, and Community Nursing in this debate and in promoting practice standards for health care and development for children in MBUs, which could be disseminated via the National Service Frameworks for Children's Services in the UK. Clear statements of development and health care aims based around the evidence of *Health for all children*²¹ would allow effective commissioning of services by Primary Care Trusts (PCTs) (England) and Local Health Boards (LHBs) (Wales) in this transitional period where services are being transferred into the NHS. An improvement in health care for all inmates is greatly needed, but the needs of small children with incarcerated mothers is a particularly pressing issue.

Undoubtedly we need to seek effective alternatives to prison, especially for this group of offenders, and the British government has made a start in this direction, with tagging and community sentencing. As yet, no provision is made for the young children of male prisoners who are their single handed carers, but

the interests of children may drive the development of such provision. Opening of more MBUs in a greater geographical spread may enable those mothers who have supportive family to draw on them, and to arrange more satisfactory separation planning to occur.

A further possibility if the age range were to be extended is that children over the age of 18 months might be looked after during the day by child minders in the community, returning to their mothers at night. This would replicate the pattern that is found in many families where both parents are working, and would give the mothers in prison the chance to be with their children at the all important times of getting up and going to bed.

Alternative solutions may be necessary for foreign national prisoners who do not have supportive families in this country and often fear that their children will be victimised by the drug barons for their (the mother's) "failure" if they are returned to their own country.

CONCLUSIONS

We are pleased that it is now policy for a care plan which identifies the ongoing needs and possible separation strategy to be agreed at the time of admission of any child to an MBU. However, professional debate and research is needed to increase the evidence base for policy making on the upper age limit for a child to remain in an MBU.

With the imminent transfer of the prison health service to the NHS, the RCPCH should take a lead role in coordinating advice to Primary Care Trusts (England) and Local Health Boards (Wales) so that they can commission effective surveillance and health care for this group of children in the locations of MBUs at women's prisons.

Arch Dis Child 2004;**89**:896–898.

doi: 10.1136/adc.2003.037382

Authors' affiliations

D Black, Hon. Consultant Child and Adolescent Psychiatrist, Traumatic Stress Clinic, London and Royal Free Hospital, London, UK

H Payne, Consultant Paediatrician, Ystrad Mynach Hospital, Caerphilly; Senior Lecturer in Child Health, University of Wales College of Medicine, Heath Park, Cardiff CF14 4XN, UK

R Lansdown, Chartered Educational and Clinical Child Psychologist, lately Great Ormond St Hospital for Children, London, UK

A Gregoire, Consultant/Hon. Senior Lecturer in Perinatal Psychiatry, Southampton, UK

Correspondence to: Dr H Payne, Consultant Paediatrician, Ystrad Mynach Hospital,

Caerphilly, Senior Lecturer in Child Health, University of Wales College of Medicine, Heath Park, Cardiff CF14 4XN, UK; payneeh@cardiff.ac.uk

Competing interests: Dora Black was a member of the HM Prison Service Review Committee that produced "Report of a Review of Principles, Policies and Procedures on Mothers and Babies/Children in Prison, July 1999"

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Medical research

Legal aspects of records based medical research

S E Parkes

Ethical medical research must continue despite the legal problems of records based medical research

All that may come to my knowledge in the exercise of my profession... which ought not to be spread abroad, I will keep secret and will never reveal (Hippocratic Oath)

Patient confidentiality is a fundamental component of medicine, but as late as 1994 the Royal College of Physicians determined that there was a duty to use available information for the general good where that could be done without detriment to individuals.¹ The British Medical Association Ethical Committee in 1988 said that information could be used without consent as long as a local research ethics committee had approved the study.² In 1997, Doyal³ proposed that epidemiological research, involving only access to medical records, should be an exception to the requirement for informed patient consent.

SO WHAT'S THE (LEGISLATIVE) PROBLEM?

Data Protection Act 1998

The situation was radically modified in March 2000, when the Data Protection Act 1998 (DPA)⁴ came into force in the UK, thus curtailing the relative freedom which had previously been enjoyed by medical researchers. The DPA was designed to protect the rights of individuals with regard to the confidentiality of their information and its implication was that no identifiable data on living individuals should be handled or disclosed without the explicit consent of the subject. Although the Data Commissioner said that the DPA should not be seen as an obstacle to medical research, that is the present situation.

Subsequent legislation and the Patient Information Advisory Group

The cancer registration establishment was the first body to voice concerns

over the implications of the DPA, after the General Medical Council (GMC) issued its own guidance in September 2000. Their interpretation effectively prohibited the automatic reporting of cancer cases to the local registry without the patient's consent. The system had been in effect for over 50 years, with no adverse consequences and many benefits, but this ruling placed the whole process of cancer monitoring in the UK in jeopardy, implying that doctors who reported cases without consent might be prosecuted. However, after much criticism, the GMC agreed to modify its guidance, which it finally did in April 2004, reflecting the effects of subsequent legislation.⁵

In 2001, the Government passed the Health and Social Care Act 2001,⁶ giving the Secretary of State power to allow the use of identifiable data in specific circumstances.⁷ The Patient Information Advisory Group (PIAG) was then established to administer these powers and to consider applications for the use of identifiable patient data without consent, many of which have been turned down. It has however approved the continuation of cancer registration, the Public Health Laboratory Service, and four national databases, on a temporary basis and with conditions. Strobl *et al*⁸ hoped that PIAG might provide clear guidance for researchers, but it has only dealt with individual applications and has provided no general solutions, except to recommend that researchers and registries work towards data anonymisation or patient consent.⁹

The Human Rights Act 1998

The Human Rights Act 1998 has also contributed to the debate, as jurisprudence has decreed that medical records are covered by Article 8 which deals with the rights of the individual regarding home, family life, and privacy. The only exemption from obtaining consent for access to medical records is that this should be in the interests of the

protection of health, but it must also be legitimate and necessary.

IS CONSENT NECESSARY?

A cardinal rule of population based epidemiological disease research is that data ascertainment should be complete for the analysis to have statistical validity. However, under the new legislation, consent to data handling is the major issue. The Information Commissioner herself stated that "It is a major misconception that the Act always requires the consent of data subjects..."¹⁰, but she also says that there is an implied requirement to obtain consent.¹⁰

The concept of patient consent is a familiar one—for diagnostic tests, treatment, recruitment into clinical trials—but how many clinicians would feel that it was necessary for historical research involving only inspection of case notes? Nowadays most consultants maintain databases of patients treated by them and their predecessors and regularly ask their juniors and non-medical personnel to undertake studies on past cases with whom they themselves have had no contact. Under the new legislation this represents disclosure of identifiable information and requires consent.

However, section 33 of the DPA is an important exemption clause in the area of records based research, providing specifically for historical research and allowing the disclosure of data from records previously collected for another purpose (that is, research use was not envisaged) as long as various conditions are met.¹¹ These include "not supporting measures or decisions with regard to particular individuals"—the meaning of this in a medical context is unclear, since, particularly in rare diseases, past experience can direct current and future practice. The others are: not causing distress and not identifying individuals in results or publications. These have long been standards automatically adhered to, but now the integrity of the medical profession has been called into question and doubts raised as to the legality of research. Although section 33 appears to solve the problem of archival data, current records which will be used for research must be collected and processed "fairly and lawfully", thus requiring patient consent and the giving of detailed information about collection and disclosure of the data.

What is consent?

The issue of consent, whilst apparently simple, is fraught with confusion. For years we have operated under the rule of implied consent but this is no longer

enough and the DPA has introduced the term "explicit" consent for health information. However, no definition is given and even the GMC stated that this could be either written or verbal. Obtaining consent to the use of information from current and future patients could theoretically be introduced (although difficult enough to administer), but what of those who refuse, or past patients whose information is already recorded and used in old registries and databases?

The early advice of the Information Commissioner's Office (personal communication, 2000) was that all identifiers should be removed, if consent could not be obtained because this would involve "disproportionate effort". There is as yet no official definition of this, although it includes such reasons as cost, manpower, size of population, and untraceable patients. Proportionality is a very important issue and can be argued to justify large scale, retrospective studies of old records without consent. Confusingly, the Department of Health has recently stated¹² that for research using identifiable data, explicit patient consent must "normally" be obtained. What do they regard as abnormal? Presumably, although they do not make this clear, this statement applies only to records currently being created.

Long term implications of consent

Let us assume we do start to ask for consent now—what do we ask for, where, when, how, and from whom? It is felt unlikely that a broad question such as "Do you consent to your [child's] data being stored and used for research in the future?" would be legally acceptable, and yet it is obviously not feasible to go back to each family when a new research question arises (proportionality again). Another issue is that it would be the parents who would initially give consent for their child's data and it would again not be practicable to approach all children when they reached the age of 18 to renew that consent. The likelihood that a proportion would refuse has obvious implications for the success of population based studies. Thus a more supportive and flexible official definition of consent in this context is required.

ANONYMISATION

It is important to remember that the DPA makes no objection to the use of anonymised information and the Information Commissioner recommends that, in the absence of consent, all identifiers should be removed "so as not to act unfairly with regard to the individual". But the problems with

anonymisation are obvious. Where subsequent information is obtained from another source, which is common in the case of disease registers, how would the records be linked? The current proposal is to use the NHS number, but until this appears on all documents, for example, pathology reports and death certificates, this will not be possible. And what of patients from overseas, whom we often see in the arena of specialist paediatric disease, who do not have an NHS number? The biggest problem is that the Information Commissioner still regards the NHS number as an identifier,¹³ so until it can be legally deemed anonymous, can be transcribed totally accurately, and achieves 100% coverage, research could be statistically invalid and public health monitoring insecure. Where researchers need access to hospital case notes, anonymisation is impossible, even though they ultimately remove the identifiers from the recorded data.

INFORMING PATIENTS

The overriding advice from the Information Commissioner's Office is that data should be obtained fairly. This means in effect that current patients should be given full details as to which information is being recorded, why, who will have access to it, what it will be used for, and what will happen to it once it has been used. Medical records are primarily created to provide an account of diagnosis and care. The fact that the information may subsequently be used for research must be explained to the patient in appropriate language at an appropriate time, most easily achieved in an information leaflet. Importantly, the patient must be given the opportunity to object. The Medical Research Council has laid out guidelines as to the information to be given.¹⁴ As for old records, those patients who can be contacted should be given the information, unless the disproportionate effort clause applies, in which case the data may be used under the terms of section 33.¹⁰

CONCLUSION—IS THERE ONE?

Despite all of the discussion, there is still no right answer. The three options which have been distilled from all the arguments put forward are: consent/assent, anonymisation, or use under a public interest mandate,¹⁵ but each is unsatisfactory and provides more problems than solutions. Most people would agree that health research is unquestionably in the public interest, but legal use of identifiable information under this mandate has previously

only been decided in individual instances.

All of this illustrates the basic conflict between a doctor's duty to keep patients' information confidential and that to pursue research into the causes, treatment, and outcomes of disease. If there had been no research over the last few hundred years, we should still be living in an age of high infant and child mortality and premature adult deaths from preventable disease. The public want and, more importantly, expect advances in medicine and surely understand that these can only take place by studying past experience. Although the age of "Trust me, I'm a doctor" is gone and recent unfortunate circumstances in the paediatric domain have shaken public confidence, expectations of progress still exist. Experience has shown that the public, including parents, would agree to their and their children's being involved in research if they had been told.

There is an extensive body of literature on this subject, which will no doubt increase. Coleman *et al* have presented a comprehensive summary¹⁶ of the developments, arguments, and opinions, illustrating in depth the confusion which still exists. They propose that further legislation to preserve vital public health monitoring and to protect medical research should be passed.

Until such time as there is more explicit, consistent Government and professional guidance as to when and what kind of consent is necessary, patient information is the key. We must be open with our patients, their families, and the wider public in order to restore their trust. Ethical medical research must be allowed to continue without impediment and with full professional backing and legal support. In the meantime, must we wait for a test case to clarify matters? Any volunteers?

Arch Dis Child 2004;**89**:899–901.
doi: 10.1136/adc.2003.045666

Correspondence to: S E Parkes, WMRCTR, Birmingham Children's Hospital NHS Trust, Steelhouse Lane, Birmingham, B4 6NH, UK; sheila.parkes@bch.nhs.uk

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IMAGES IN PAEDIATRICS.....

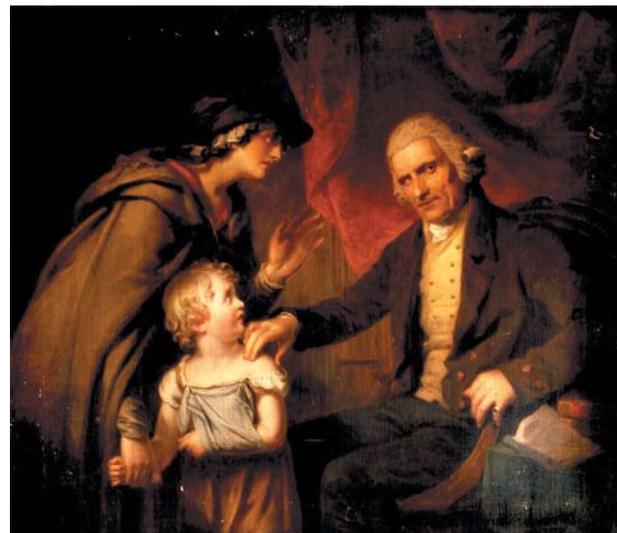
doi: 10.1136/adc.2004.060665

William Hey (1736–1819) and child patient

Hidden from public view in many of our hospitals are works of art that reflect a rich medical and social history. From an era long before paediatrics became a specialty in its own right, there are few representations of the care of children. One exception is this painting of Leeds surgeon William Hey (1736–1819), remembered for the eponymous Hey's saw and Hey's ligament, together with his original descriptions of internal derangement of the knee.¹ Hey worked for nearly 60 years, not only as apothecary-surgeon but also as a man-midwife and "paediatrician",² describing both infantile hernia and congenital syphilis. This portrait by William Allen was commissioned in 1816 as a testimony to Hey's humanitarianism. He is shown examining a child with a fractured clavicle from the estate village of Harewood just outside Leeds. Incognito and observing the consultation is Lady Harewood, bent on testing Hey's reputation for indifference to social circumstances and class when it came to medical duty. This charming image portrays both compassion and tenderness, a fitting example to those of us caring for children today. Hey's outlook was no doubt moulded by his religious upbringing, personal experience of sickness and loss among his own children, and his desire that new discoveries in science and medicine should lessen the suffering of mankind. Hey's marked squint can be readily appreciated; it resulted from a childhood penknife injury to his right eye. However, monocular vision proved no barrier to him becoming a famous surgeon, his writings recognised throughout Europe. He maintained perfect vision in his left eye until his death from a perforated colon at the age of 83. The portrait hangs in the Boardroom of the General Infirmary at Leeds, a hospital that originated through the endeavours of its eighteenth century founders, prominent among whom was Hey himself.

N Leadbetter

Leeds University School of Medicine, Department of Paediatrics and Child Health, The Children's Centre, The General Infirmary at Leeds, Leeds, UK



J W L Puntis

The General Infirmary at Leeds, Department of Paediatrics and Child Health, The Children's Centre, The General Infirmary at Leeds, Leeds, UK

Correspondence to: Dr J W L Puntis, The General Infirmary at Leeds, Department of Paediatrics and Child Health, The Children's Centre, The General Infirmary at Leeds, Clarendon Wing, Belmont Grove, Leeds LS2 9NS, UK; john.puntis@leedsth.nhs.uk

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