# Evidence-based best practice for the care of young people in Hospital

Russel Viner & Mark Keane

# Caring for Children in the Health Services

*Caring for Children in the Health Services* (CCHS) is an informal consortium led by a lay chairman and including representatives of consumer, medical, nursing and management groups:

- Action for Sick Children
- Royal College of Paediatrics and Child Health
- Royal College of Nursing of the United Kingdom
- the NHS Confederation.

CCHS is independent of the Department of Health, however it ensures that governmental and non-governmental agencies are kept informed of its research and recommendations.

## THE AIMS OF CCHS ARE:

1. to undertake and publish research aimed at improving the care of children and young people within the NHS
2. to produce practical guidelines for health professionals in relation to children's services
3. to use the resources of each constituent organisation to lobby for implementations of research findings.

*CCHS Reports: CCHS has previously published the following reports*

Where are the Children (1987)
Just for the day (1991)
Hidden Children (1988)
Bridging the Gaps (1993)
Parents staying overnight with their children in hospital

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Photographs
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# FOREWORD

*Lady Caroline Rhys Williams, Chairman,*
*Caring for Children in Health Services.*

'Youth Matters' is the fifth report produced by Caring for Children in the Health Services and arises from our realisation that owing to the many clinical advances, there are now many more sick children surviving into adolescence who need appropriate care when they are in hospital.

A year ago we sent a questionnaire to all Health Autorities who confirmed our worst fears. As you will see in this report very few of them required their Hospital Trusts to provide specific care or facilities for young people.

These findings led CCHS to seek funding for a systematic review of the literature and we were enormously grateful when the Nuffield Foundation gave us a generous grant. The research has been masterminded and written up by Dr Russell Viner, Director of Adolescent Medicine at University College London Hospitals and Great Ormond Street Hospital for Children. We are extremely grateful to him and his research fellow Mark Keane for all the work they have done.

Youth Matters will help doctors, nurses and managers to adopt best practice when setting up new services or improving existing ones for young people. It is important that young people get a better deal from the National Health Service.

The next stages of the project will be to survey existing adolescent facilities in selected parts of the country, and to conduct a survey of young people both those who have had stays in hospital and those who have not in order to know about their experiences and expectations of ward life and then to define quality standards. Our work will begin as soon as we have found suitable funding.

CCHS commends this report to you and hopes you will use it.

Caroline Rhys Williams.

# ACKNOWLEDGEMENTS

We would like to thank all Health Authorities and Boards who participated in Stage I of the research.

Stage II of this work and the publication of this report was generously funded by the Nuffield Foundation.

We would particularly like to thank former CCHS members, Yvonne Mouncer of the NHS Confederation and Carole Myer of Action for Sick Children for their work in CHSS and in making this report possible.

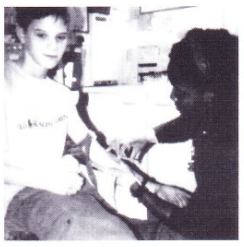
The review was carried out by Dr. Russell Viner, Director of Adolescent Medicine, University College of London Hospitals and Great Ormond Street Hospital, and Mark Keane, Research Fellow at the institute of Child Health, University College of London.

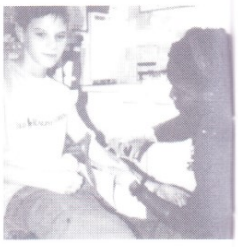
We would like to thank Anna Gregorowski for providing the section on the role of the adolescent liaison nurse, and Matthew Davies and the young people of the Middlesex Hospital for providing photographs used in this report.

We would also like to thank the editor of the Nursing Times for allowing us to reprint *Like it or lump it* (p.10-11).

# ABBREVIATIONS

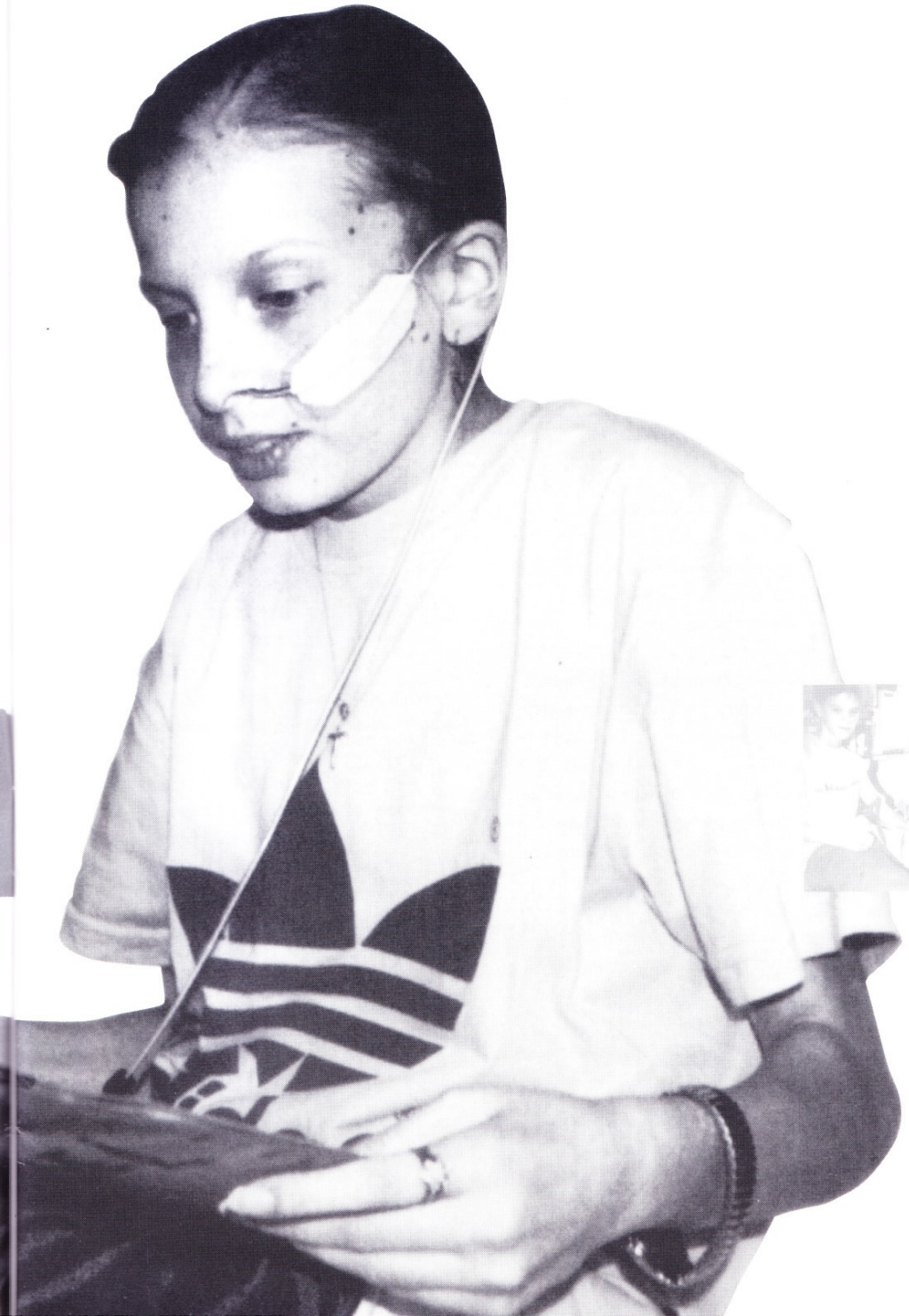
| | |
|---|---|
| CCHS | Caring for Children in the Health Services |
| AU | Adolescent Unit |
| CNS | Clinical nurse specialist |
| UK | United Kingdom |
| SAM | Society or Adolescent Medicine |

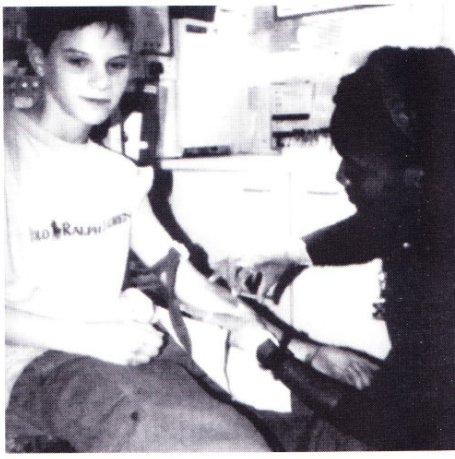




# SUMMARY

- The commissioning and provision of care to adolescents in hospital is poor. Only 10% of health authorities and boards in the UK have specifications for adolescent physical health care, and only 40% have specifications for adolescent mental health.
- The co-location of all adolescents within a dedicated adolescent unit within a hospital is best practice. **The present dispersal of adolescents throughout different speciality wards caters for the convenience of the medical and nursing staff rather than for the needs of the patient.**
- Adolescent inpatient units should be established in most District General Hospitals in the UK. 1997-98 data shows that 15 adolescent beds are needed for each 250 000 population, yet only 8% of health authorities contain adolescent provider units in their hospitals.
- This report provides evidence-based guidance for the establishment and operation of adolescent inpatient units, and a foundation on which clinical governance for young people can be based.





# GUIDANCE

## GUIDANCE FOR COMMISSIONING AUTHORITIES

### GENERAL ISSUES AND NEED

**1.1** Specific service specifications for adolescent care in hospital are an essential part of best practice for the care of young people. Each commissioning authority must develop specifications for adolescent physical health.

**1.2** Dedicated adolescent units are cost effective and provide best quality care for adolescent patients:

- young people overwhelmingly support separate dedicated facilities
- the psychosocial and developmental needs of young people are very different to those of children or adults, and are unlikely to be met in children's or adult wards.
- the common needs of adolescence unite sick young people more than the particular needs of their diseases separate them.
- facilities should be designed to meet the needs of young people rather than their doctors and nurses (i.e. disease or speciality-based wards).
- adolescent units improve health outcomes through improved adherence behaviours, shorter duration of stay, reduction of psychological morbidity and improved control of chronic illness.
- improved training of medical and nursing staff in dealing with young people will improve adolescent health outcomes.
- the grouping of adolescent patients together facilitates research and development.
- the adolescent unit will free adult beds in areas of need.

**1.3** Commissioning authorities should have a nominated commissioner for young people. This may be the same person nominated for child health, however the different developmental needs of young people must be recognised.

**1.4** Commissioners should develop a strategy for commissioning adolescent health in the following area:

- hospital based secondary services - including A&E, outpatients and intensive care
- tertiary services
- mental health services
- This strategy should be part of an integrated adolescent health strategy including primary and community care.

**1.5** Effective adolescent services can only be developed in collaboration with education, social services, local authorities and the youth justice system. Commissioners should develop joint local strategies with all stakeholders in adolescent health.

### NEEDS ASSESSMENT AND AUDIT

**2.1** A detailed needs assessment should be undertaken for young people covering the following areas:

- all young people aged 12-19 years
- young people with chronic illness or life threatening illness (e.g. cancer)
- young people with disabilities and complex needs
- "looked after" young people

**2.2** Accurate statistics must be collected about adolescent services in order to draw up contracts and monitor outcomes

**2.3** Key indicators should be identified for monitoring quality and health outcomes of services provided

**2.4** Young people's views on services must be gathered to ensure that services meet consumer needs. Methods of seeking young people's views must:

- cover the range of ages of target young people
- ensure the confidentiality of gathered opinion
- inform participants of the use of gathered opinion - and ensure as much as possible that young people's opinions are actually listened to
- include disabled adolescents
- provide feedback for those who participate

**2.5** An accurate report on the care of young people should be received from all providers looking after young people in hospital.

### SPECIFICATION FOR CANTRACTS

**3.1** Young people 12-19 years should be housed on a dedicated adolescent inpatient unit that meets the psychosocial needs of adolescents.

**3.2** District general hospitals should establish an adolescent unit of 12 to 15 beds for each 250 000 of the general population.

**3.3** Suitable young people for admission to such a unit include:

- all young people 12-19 years with acute or chronic illness, excluding obstetric cases which are best managed on obstetric units
- young people with psychological disturbance of social or environmental origin e.g. those with self-harming behaviour and behavioural disorders NB young people with major psychiatric diagnoses e.g. psychoses or anorexia nervosa should be managed in specialised adolescent mental health units
- young people whose behaviour makes them difficult to contain on children's wards. Such patients should be managed in a specialist regional adolescent unit.

**3.4** Staffing levels for the adolescent unit must provide:

- adequate mental health staff resources
- adequate recreation resources
- facilitate education providing adequate teaching and vocational resources

**3.5** Where a dedicated adolescent inpatient facility is not possible, hospital-wide services and policies for young people must be developed, including education and psychosocial support services.

**3.6** All paediatric services should have transition plans in place for the transfer of patients to adult care

# GUIDANCE FOR PROVIDERS

## THE ADOLESCENT-FRIENDLY HOSPITAL

**1.1** Providers must recognise adolescents as a group with specific health needs, requiring special provision for:

1. their overall health care in hospital
2. the psychosocial aspects of illness
3. education and vocational training
4. transition to adult care
5. health promotion

**1.2** Hospital-wide policies for the care of young people must be developed for the care of young people both within a dedicated adolescent unit and in other wards, A&E, intensive care and outpatients.

**1.3** The planning of adolescent services must include representatives of young people and all groups using the unit. The ward environment must be planned according to needs of young people rather than merely clinical need.

**1.4** Regular clinical audit and assessment of user satisfaction must be undertaken to ensure quality of care.

## INPATIENT SERVICES

**2.1** An adolescent inpatient unit of 12 to 15 beds should be established in each hospital serving approximately 250 000 persons.

**2.2** This unit should be a free-standing ward adjacent to the paediatric service. A less desirable option is the development of a section of the children's ward as an adolescent area. This area should contain no less than 4 beds.

**2.3** The adolescent unit should be multi-speciality, taking all adolescents expect where the need for highly intensive nursing care outweighs the benefits of being with other young people e.g. intensive care, cardiac and neurosurgical post-operative care etc.

**2.4** Complex medical and surgical patients can be effectively managed on a multi-speciality adolescent ward if the nursing staff hold a wide portfolio of skills and there is good communication with and access for subspeciality medical and specialist nursing staff.

**2.5** The ward should operate on a "normalising" model which regonises the normality of problems resulting from hospitalisation and chronic illness. The involvement of psychosocial and mental health staff should be seen as a normal part of ward routines and treatment regimens rather than being seen as a sign of pathological deviance.

## PHYSICAL WARD ENVIRONMENT

**3.1** In planning the physical environment, the following guidelines should be noted:

- bedroom sizes should range from 1 to 4 beds. Single rooms should only make up a third of the total beds.
- young people should be encouraged to personalise their bed spaces
- parent accommodation should be equal to a third of the patient beds
- privacy is essential when planning all facilities- particulary interview rooms, treatment areas, and bathroom and toilet facilities

**3.2** The following spaces are needed in addition to bed and staff areas:

1. recreation room - separate from clinical areas and from the school room
2. school room - this may also act as a resource room for computer and information technology facilities
3. quiet room - separate from recreation facilities
4. kitchen and laundry facilities
5. interview room
6. meeting room for multi-disciplinary team meetings

**3.3** All facilities must include consideration of disabled access.

## OPERATIONAL POLICIES

**4.1** Admission policies must be flexible and include the mature 11 year old to the immature 19 year old. However:

- intellectually impaired adults are not suitable patients for an adolescent ward
- the ward must be able to handle behaviourally disturbed young people
- admissions for major psychiatric disorders are not recommended

**4.2** House rules should address matters as smoking, wearing of own clothes, "lights out" times and visiting hours in language accessible to young people. The Rules should be available in other languages.

**4.3** A combined recreational - educational program should be established by the teacher and activities workers. This program should address educational, vocational, self - esteem and independence issues as well as the need for leisure activities.

**4.4** Flexible visiting hours are essential with free visiting for parents and peers. However, unlike children's wards, the constant presence of parents may be counter-therapeutic and should not be encouraged unless the young person is very ill.

**4.5** Young people must be involved in all decisions about their care, and due consideration must be given to issues of confidentiality and informed consent.

**4.6** Self-care by young people should be encouraged, and the development of self - medication policies should be considered.

## STAFFING

**5.1** All staff working with young people must have:

- an interest in and commitment to the adolescent age-group, with special skills in communicating and in empathising with adolescents
- familiarity with the psycho-dynamics or tasks of adolescents
- awareness of personal-professional boundaries with young people
- a commitment to working as part of a multi-disciplinary team
- a commitment to ongoing development and education

**5.2** A designated consultant should have responsibility for the welfare of the adolescent unit and its patients. The designated consultant should:

- share administrative responsibility for the ward budget and staff with the senior ward nurse
- have overall clinical responsibility for all patients on the ward while patients primarily remain under their speciality consultant
- undertake weekly multi-disciplinary rounds in which the psychosocial needs of all patients are addressed

**5.3** The following minimum staff will be needed for a 15 bed adolescent unit:

1. nursing staff to provide a mix of general and registered children's nurses. Staff with combined general/children's and mental health training are desirable.
2. 0.5 whole-time equivalent (WTE) social worker.
3. 0.5 WTE psychologist or psychotherapist
4. 3 sessions of child and adolescent psychiatry
5. 0.3 WTE of each of physiotherapy, occupational therapy and dietetics
6. full-time activities/ recreation worker
7. full-time teacher (salary provided by Local Education Authority)

**5.4** Where adolescents under 16 years are nursed, there should be a minium of 2 registered children's nurses per shift.

**5.5** A range of staff ages is essential. All staff must be aware of boundary issues.

**5.6** A balance of male and female staff is important to provide role models for young people.

## EDUCATION

**6.1** The provision of adequate education facilities to continue secondary school education is essential.

**6.2** At least one full-time teacher is required for a 15 bed adolescent unit.

**6.3** Education programs must be extended to include vocational counselling and work experience programs. Facilitating the entry of chronically ill young people into the workforce is part of the role of the adolescent unit

**6.4** Investment in computing and information technology is essential for quality education programs and for vocational guidance in information technology.

## OUTPATIENT AREAS

**7.1** Specific adolescent outpatient areas are not necessary, however clinicians who see large numbers of young people should concentrate adolescents in regular adolescent clinics after school hours.

## ADOLESCENTS NURSED IN ADULT OR CHILDREN'S WARDS

**8.1** Young people not nursed in specific adolescent facilities require:

- single room accommodation
- access to education and other psychosocial facilities
- choice of adult or children's ward for those 14 to 16 years of age

**8.2** Children's services with large numbers of young people but without dedicated adolescent facilities need to develop adolescent liaison services and an adolescent recreation centre

## TRANSITION

**9.1** A transition policy must be developed for all paediatric general and speciality clinics. Where large numbers of young people are being transferred, a transition program run by the clinical nurse specialist should be developed.

**9.2** Administrative and management as well as clinical links between trusts are essential for effective transition.

## MENTAL HEALTH GUIDELINES

No attempt has been made here to develop guidelines for commissioning or providing adolescent mental health. Commissioners and providers are referred to existing document.

# INTRODUCTION

*"Adolescent health needs, in regard to both health promotion and treatment of sickness are given insufficient priority and lack focus, with poorly developed services. Services for adolescents should be given greater focus and priority. The transfer of young people, particularly those with special health needs, from child to adult services requires specific attention."*

House Of Commons Select Committee on Health, Fifth Report 1997, p. xxxvi[1]

"Teenagers are the forgotten people of hospital medicine."[2]

The unique health needs of adolescents have been documented since the early twentieth century. The management of health and disease in adolescence requires integration of medical, social and psychological elements within a framework that recognises the developmental imperatives of the adolescent period. Perhaps more than any other period in life, the optimum medical treatment of adolescents demands a holistic approach that recognises all facets of the social and cultural welfare of the patient as well as their physical and mental well-being.

In North America and Australia, a distinct speciality of Adolescent Medicine has been developed in response to the complex need of this age group. Dedicated secondary and tertiary adolescent facilities have become a standard feature of both children's and adult hospitals in those countries.[3,4] Similar services are beginning to be developed in many European countries.[5] In the UK, in contrast, adolescents are relatively poorly served at all levels of the Health Service.[6]

The need for dedicated hospital facilities for adolescent patients in the UK has been stressed repeatedly since 1959.[7-9] Brief statements on standards of care for young people in hospital were published in the late 1980s,[8,10,1] but authoritative information to guide health professionals and planners on the development and operation of services for adolescents is scarce. Forty years after the Platt Report (1959) acknowledged the need for specialised health care facilities for young people [9], no national studies have been undertaken to identify available services, evaluate the provision of care or formulate co-ordinated strategies to meet the needs of adolescents [12].

Seven years after the introduction of the purchaser-provider split within the NHS, it is clear that purchasers and commissioners do not have necessary commitment or expertise in purchasing services which address the specific health needs of adolescents requiring hospital treatment.[1] This report provides evidence-based guidelines on the need for adolescent services in UK hospitals and on best practice for the care of young people in the hospital environment.

## THE NEED

The need is clear for improved adolescent health services at all levels of health care in the UK. Young people between 10 and 19 years of age make up around 13% of the UK population.[13] Diseases with social and cultural origins such as suicide, accidents and drug related illnesses, have replaced communicable diseases as the largest source of mortality for those aged 12 to 17 years.[14] Suicide has nearly doubled in male teenagers since 1975,[15] sexually-transmitted diseases will make the next generation the most infertile in the history of humanity, and UK teenage pregnancy rates remain among the highest in the world, having failed to decline significantly in the last twenty years. The burden of chronic illness in adolescence is increasing in all developed countries as larger numbers of chronically ill children survive into the second and third decades.[16-18] For example, the prevalence of cystic fibrosis over 15 years of age in the UK more than doubled between 1977 and 1985, and currently over 85% of children with chronic illness survive to adult life.[18]

Providing efficient and effective care for adolescents with acute and chronic illnesses will be one of the great challenges for the health service in the next century. While many of the challenges must be met in primary care, improving the care of young people in hospital will have a significant impact on improving the quality of life of young people and the costs of health care in the UK. Our Healthier Nation mandates the Health Service to pay greater attention to the structural, economic, social and cultural determinants of health.[19] This challenge may be most pertinent in adolescents, in whom social and cultural factors are perhaps more important determinants of health than in any other age-group.

## CARING FOR CHILDREN IN THE HEALTH SERVICES

This work for this report has been undertaken by Caring for Children in the Health Services (CCHS), an informal consortium led by a lay chairman and including representatives of consumer, medical, nursing and management groups: Action for Sick Children, the Royal College of Paediatrics and Child Health, the Royal College of Nursing and the NHS Confederation. The aims of CCHS are to undertake and publish research aimed at improving the care of children and young people within the NHS, produce practical guidelines for health professionals in relation to children's services, and to use the resources of each constituent organisation to lobby for implementations of research findings. Previous work by CCHS has highlighted adolescent welfare in hospital as a major area for concern e.g Where are the Children? (1987) investigated the care of children and young people on adult wards, Bridging the Gaps (1993) identified the transition from paediatric to adult care as a major deficit in health service, provision, and Just for the Day (1991) addressed the needs of children and young people in regard to day procedures.

## CCHS ADOLESCENT RESEARCH STRATEGY

To redress the absence of guidelines and systemised information on the care of adolescents in hospital, CCHS began in 1997 an integrated four-stage study of young people in hospital in the UK.

The first two parts of this work are presented in this report.

### Stage 1a.
### SURVEY OF HEALTH AUTHORITY AND BOARD SPECIFICATIONS FOR ADOLESCENT SERVICES

We surveyed all health authorities and boards in the UK regarding their service specifications for adolescents in hospital through a mailed questionnaire in August 1997. Both physical health and mental health were included. A 90% response rate was achieved. The survey is discussed on pp. xxxx

### Stage 1b.
### SURVEY OF ADOLESCENT BED USAGE IN HEALTH AUTHORITIES

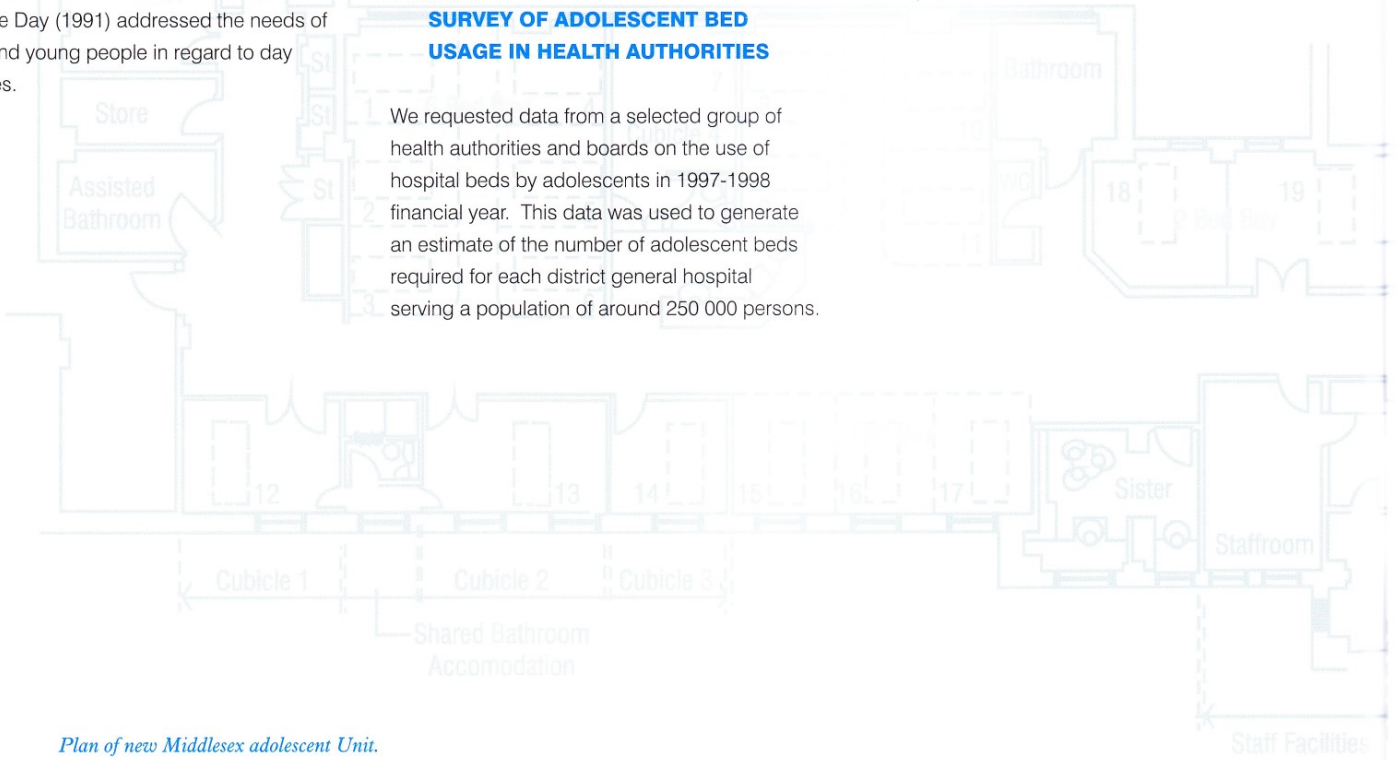
We requested data from a selected group of health authorities and boards on the use of hospital beds by adolescents in 1997-1998 financial year. This data was used to generate an estimate of the number of adolescent beds required for each district general hospital serving a population of around 250 000 persons.

The results are presented on pp. 18.

### Stage II
### SYSTEMATISED REVIEW OF THE LITERATURE ON DEVELOPMENT AND OPERATION OF ADOLESCENT SERVICES IN HOSPITAL

*Stage II of the work was generously funded by the Nuffield Foundation*

Despite the lack of guidelines on care for young people in hospital, an extensive literature does exist on the needs of hospitalised adolescents. However, this literature is fragmented and not always easily accessible. Information is scattered through many disciplines including medicine, nursing, psychology, health planning, and the literatures of the allied health professions. Some studies have never been formally published. To redress these problems and produce authoritative guidance for commissioners, purchasers and providers, a literature review using a modified systematic review methodology was undertaken from April to September 1998.




*Plan of new Middlesex adolescent Unit.*

*Stages III and IV of the work will be undertaken in 1999-2000.*

**Stage III.**

**SURVEY OF PRESENT ADOLESCENT FACILITIES IN NHS PROVIDER UNITS IN THE UK**

**Stage IV.**

**CONSULTATION EXERCISE WITH A LARGE GROUP OF ADOLESCENTS REGARDING HOSPITAL SERVICES.**

The Health of the Young Nation guidelines recognised the rights of young people to be involved in planning health services, and a number of projects have been undertaken involving young people in planning community health services. However, hospital services have been excluded from this consultation process.[20]

A report containing Stages III and IV will be published in 1999-2000.

## A BRIEF NOTE ON ADOLESCENCE

Adolescence is best described as a bio-psycho-social construct i.e. the process of maturity in biological, psychological and social terms. However, many (often contradictory) chronological definitions of adolescence exist. For the purposes of this report we used a flexible definition of adolescence, setting the bounds to include the mature 10 year old and immature 20 year old.

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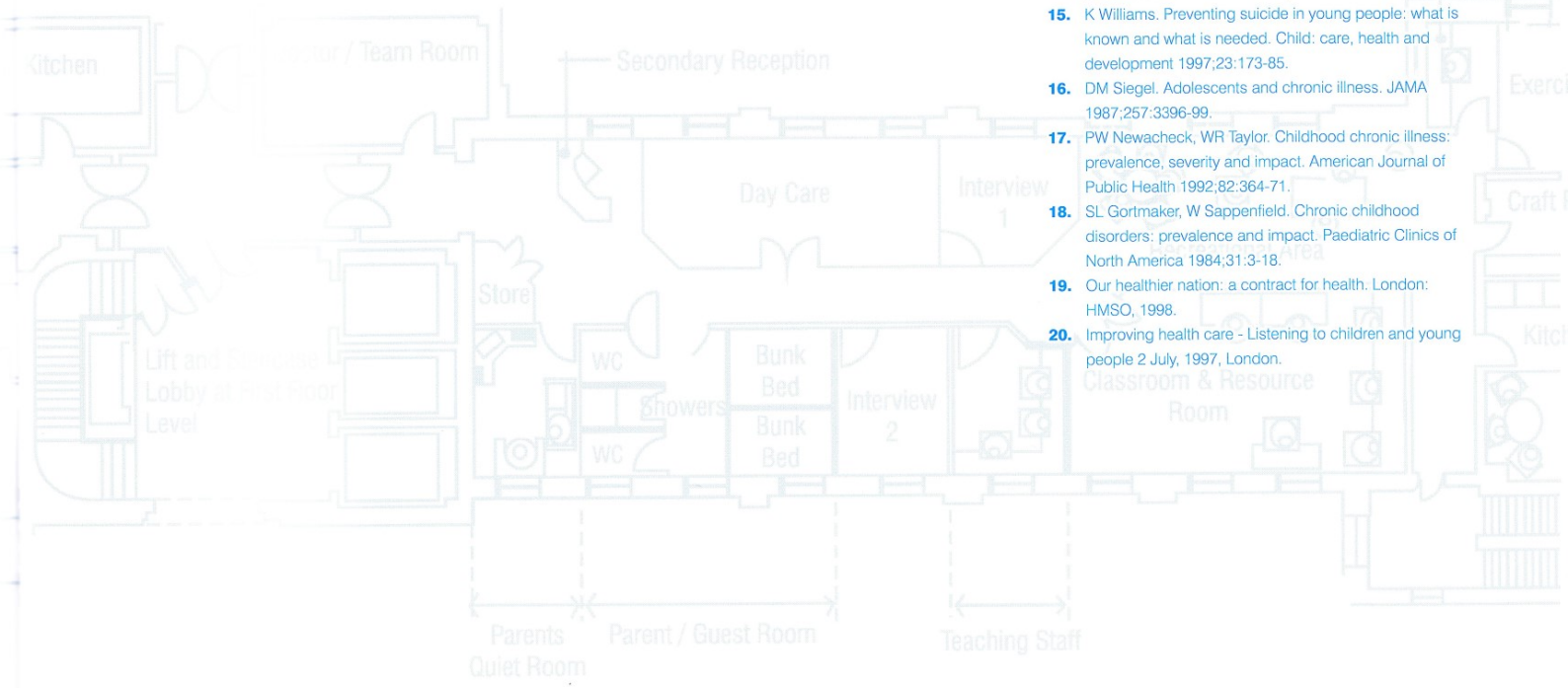

# LIKE IT OR LUMP IT

*Daniel Steven, aged 14, describes his not-too-comic relief on being admitted to a children's ward before an operation on his lymph gland.*

After spending two hours in casualty being prodded by many white-coated adults, I'm almost thankful to be told that my enlarged lymph gland needs an operation and I am admitted. It means also Mother can stop telling me dreadful jokes to keep me cheerful - what a relief.

When I come out of the lift on the third floor, shocks are in store. One: Horrible sense of déjá vu- this is where I had my appendix out when I was 10. My new bed is dead opposite the one I was in then. Two: The same Snoopy mobile hangs from the ceiling. The ward is full of Lego, snotty two-year-olds and many tired looking mothers. Three: A young nurse greets me with, "hello Darren" (my name is Daniel), 'put on your pyjamas and pop into bed - the doctor will be round soon.' I don't know why I have to wear pyjamas now, so they can look at the lump in my neck again - it's visible under a balaclava helmet. And I don't have my pyjamas!

Mother rushes off to Marks and Spencer. Meanwhile, I am given a hospital gown which itches and yes, all the jokes are true: your bum hangs out at the back. The young nurse is kind enough to draw the curtains round my bed for me to disrobe, but the tired-looking mothers stare at me afterwards.

Mother returns with navy pyjamas; this time I change in the toilet. I am now 'nil by mouth'- mother explains this is so I don't throw up on the operating table. The TV in the middle of the room is on too loud. Fellow patients play with Lego and Alex in the bed next to me pees on the floor. He has eczema and he is crabby.

At eight I am told by a new nurse that I won't be operated on tonight, so I can eat and what would I like? Before I can find the words for 'doner kebab' she brings me the only yoghurt from the ward fridge. It tastes good, but I am grateful for the Mars bars in Mother's handbag. Resolve to forgive her for awful sense of humour earlier.

The night is dreadful. The light is on all the time, my bed is covered in concrete blankets and Alex is even more crabby. The night nurses pay no attention to him, so I read him a story about magical crocodiles while he scratches. When the day nurses arrive they tell me I'm a good kid. I am 14, not a kid.

Mother is back at daybreak, so is 'nil by mouth'. Then it's all hunger, boredom and throbbing in my neck, very loud TV and Lego. The play nurse comes and tells me there is a play room, but seems relieved to see I have got my Walkman. I am listening to Guns N' Roses and she tells me: 'That's nice, my son likes computer games too' (I am still trying to figure that out).

Finally it's operation time, but first there is the pre-med. For some reason that stuck in my head from the previous time as horribly painful, so I tell the nurse. She tells me I should look away while she gives me the injection. I tell her I want to see when it's coming, but she insists it's better her way. When the needle touches my skin I jump and knock it out of her hand. The next time it hurts again, but feels good straight after.

The porter who takes me down to the theatre is nice but ruins it all by telling the theatre nurse he hopes she will be OK. I have long hair, but I don't look like a girl. The nurse puts him right. After the operation she spreads Vaseline on my mouth, but won't give me a drink. She warns me that there is a small pipe in my neck to drain the wound, which saves me from thinking they've turned me into Frankenstein's monster.

Back at Franklin Ward, all is noise. The TV is on, the room is full of Lego, tired-looking mothers and two-year-olds who pee on the floor. I sleep anyway. I get supper - omelette and chips - which I don't want. I don't even want my Mother's Mars bars. Alex yells all night; someone else's turn to do the magical crocodile routine.

Breakfast tastes good and permission to go to the loo is granted by another new nurse. The play nurse comes back but passes me by with a smile. She is probably still puzzling over Guns N' Roses. The new nurse comes back and asks me if I have been to the toilet. She also feels moved to ask me if I had a wash while I was in the bathroom. I truthfully answer yes. I want to ask her the same, but think she would find it impertinent (great word).

Later on they come to take my 'drain' out. It doesn't hurt and it's only covered by a plaster, so there will be nothing to show my friends to indicate my immense suffering!

I am told I can go home after the doctors have looked at me again, which turns out to be seven in the evening. Boredom takes on a new meaning that day and even Mother runs out of dreadful jokes. I am beginning to feel thankful for the loud TV. There is no one at the desk when we leave, so no one say's 'goodbye Darren'.

*P.S: My friend Ewan went to the same hospital three weeks later to have his tonsils out. I was dead jealous because he was put into a grown-up ward (because he is tall?). Their TV was on too loud also and he kept getting called Ian. But no one peed on the floor.*

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# POLICY

*"It can, presumably, be assumed that the administrative difficulties involved in providing separate accommodation for adolescents are likely to be temporary. When district hospitals are built, one may suppose that, in view of the pink circular, adolescent wards will form a recognised part of the hospital."*

Adolescents in hospital. The Hospital 1969:117-19, quote p.118-19 on implementation of Department of Health and Social Security pink circular (69)4

Official policy has paid lip service to the development of dedicated adolescent units (AU) in British hospitals since the Platt Report of 1959.
The optimistic predictions of those such as the correspondent for The Hospital quoted above have proved false as few hospital service providers have turned these suggestions into reality.

The last decade has seen a plethora of good practice guidelines developed for children's services, as the Fifth Report of the House of Commons Select Committee on Health noted in 1997.[2] In most of these reports commissioning recommendations are presented for services for "children and adolescents" as an indivisable group.[3] However, the vast majority of these focus almost completely on younger children and address the needs of adolescents only in passing.

Seven years after the introduction of the purchaser-provider split within the NHS, it is clear that purchasers and commissioners have failed to put even the inadequate existing policy recommendations on the care of adolescents in hospital into practice. The reasons for this failure are multiple.[4]

1. inadequate awareness amongst hospital staff and managers about the needs of sick adolescents resulting in failure to perceive them as a distinctive patient group
2. a lack of economic resources to build and staff dedicated adolescent units
3. a lack of trained staff dedicated to caring for sick adolescents
4. negativity among specialist medical and nursing staff about "losing" adolescent patients to a dedicated adolescent facility
5. a lack of data on the effectiveness of dedicated adolescent units in improving health outcomes and reducing health expenditure

## PRESENT POLICY STATEMENTS

Three sets of UK guidelines advise commissioners and providers on meeting the needs of adolescents in hospital.

## DEPARTMENT OF HEALTH: WELFARE OF CHILDREN AND YOUNG PEOPLE IN HOSPITAL (1991)

The Department of Health report on the *Welfare of Children and Young People In Hospital (1991)* was historically the first real attempt to address the issues of purchasing for children and adolescents in the "new" NHS.[5] While concentrating largely on young children and the development of integrated child health strategies, the cardinal principles of the 1990 report advised districts and provider hospitals that good practice required "the accommodation of adolescent patients in a separate unit from children's and adult wards within children's departments which can provide privacy, flexibility of regime and independence."[6] The report emphasised the need for recreational and socialising space for young people in hospital, the need for flexibility in identifying the age-ranges for admission to AU and in operational policy on such units, and the need for nursing staff to be appropriately trained to deal with adolescent patients.
Hospitals were advised that patients appropriate to AU included acutely ill young people as well as those with chronic illness and disabilities, young people with mental handicap, and young women and girls for confinement or termination of pregnancy.

This guidance was adopted by the Welsh Office and the Northen Ireland Office, and republished by the Scottish Office as At Home in Hospital (1993).

## ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH (FORMERLY BRITISH PAEDIATRIC ASSOCIATION): REPORT OF THE WORKING PARTY ON THE NEEDS AND CARE OF ADOLESCENTS (1985)

The British Paediatric Association *Report of the working party on the needs and care of adolescents* (1985) was the first report to set recommendations for the provision of dedicated adolescents services in district general hospitals (DGH). Short and largely anecdotal with only 20 references, the report suggested that all new DGH builds should include a specific AU. The authors argued (surprisingly) that adolescent beds could be found from the release of beds from then recent decreases in children's bed occupancy. Using figures from an unstated number of health regions, the working party suggested that around 15 adolescent beds were required for each DGH serving a population of 250,000 persons. Until now, this has been the only available estimate of bed requirements for adolescents in Britain - and agrees extremely well with the estimate of bed need reported in Stage 1 of this report (pages of Stage 1).

The first document providing guidelines for the care of young people in hospital was produced

## ACTION FOR SICK CHILDREN (FORMERLY NAWCH: NATIONAL ASSOCIATION FOR THE WELFARE OF CHILDREN IN HOSPITAL)

by NAWCH (now Action for Sick Children) in 1990: *Setting Standards for Adolescents In Hospital.* This brief report provides simple guidelines for commissioning authorities and providers on standards of care for adolescents in hospital, as well as detailing experiences from a number of AU then existing in the UK. The concept of dedicated AU is strongly supported by the report although the recommendations contained in the report are not evidenced based.

Other reports by Action for Sick Children have also tangentially addressed the needs of adolescents in hospital. *Health Services for Children and Young People: A Guide for Commissioners and Providers* (1994)[3] concentrates almost solely on the needs of children, although noting the specific needs of young people particularly in the areas of disability and the transition from paediatric to adult care.

Royal College of Nursing: Caring for Adolescents (1994) (sub 1 as the others) The Royal College of Nursing of the UK has produced brief but guidance on staff and facilities needed to care for young people in hospitals, reflecting the lead nurses have taken in the UK in developing adolescent facilities in hospitals.

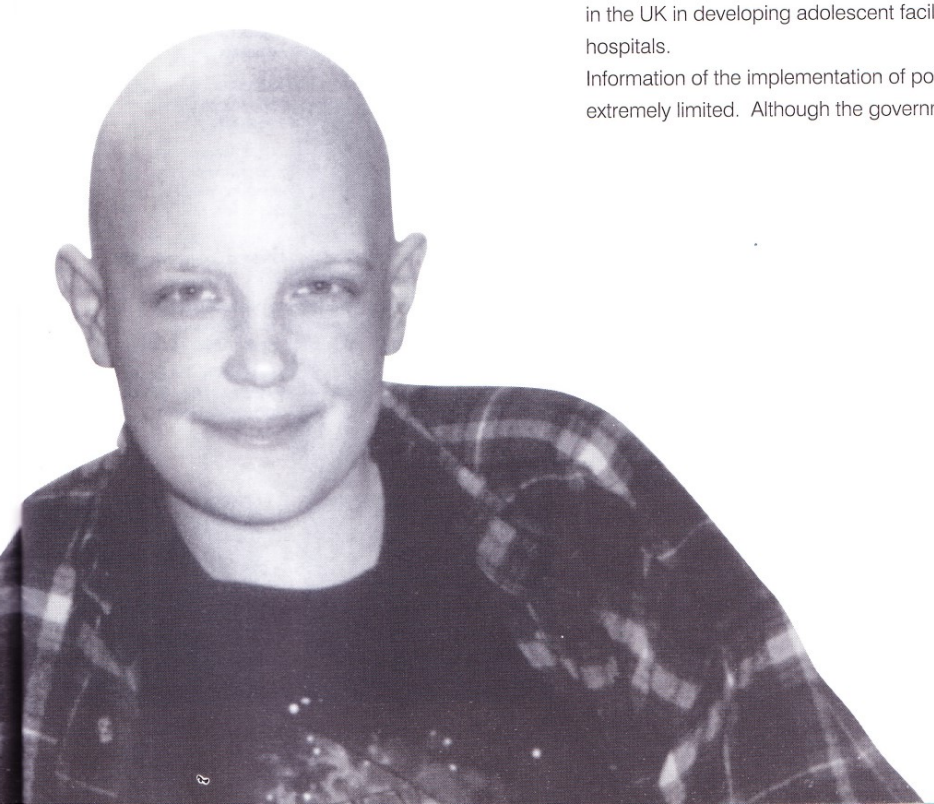
Information of the implementation of policy is extremely limited. Although the government

## IMPLEMENTATION OF POLICY

guidance in 1991 and 1993 included the provision of dedicated adolescent inpatient facilities as one of its seven cardinal principles, the Select Committee on Health noted in 1997 that "Despite the Department of Health's principles being expressed in a form which suggests that they describle levels of service which are currently available, it is clear that they indicate aspirations rather than actual achievements." (p.vii)[2]

The only information available on the implementation of policies for improved care of young people in hospital is presented in Stage 1 of this report on pages of Stage 1.

The only other information available on the implementation of mental health policy (an assessment of purchaser specifications for child and adolescent mental health in the North Thames region in 1994) concluded that "Purchasers' knowledge of the services they were purchasing was very limited. They had made little or no attempt to set quality standards or to monitor them. It is concluded that information about these services is so limited that purchasers would be unable to make informed decisions concerning changes in service patterns."[7]



## USA POLICY

In the absence of evidence based British policy on the care of adolescents in hospital, guidance may come from overseas, most particularly from the American Society for Adolescent Medicine (SAM). SAM has published two position papers on adolescents in hospital, the first in 1973 *(Characteristics of an inpatient unit for adolescents.* Clinical Paediatrics 1973;12:17-21) and a recent update in 1996 (M Fisher, M Kaufman. *Adolescent Inpatient units: A position statement of the Society for Adolescent Medicine.* Journal of Adolescent Health 1996; 18:307-8). In addition, SAM has published policy guidance on the care of adolescents with acute and chronic illness under managed care, a health service system with some similarities to Britain's.[8,9]

Guidance from SAM strongly supports the establishment of inpatient AU in both paediatric and general hospitals as the optimal approach to the delivery of developmentally appropriate health care for young people, and suggests that planning of appropriate care for adolescents in hospital takes place at all administrative levels - local, regional and national. In hospitals with insufficient admissions to warrant a separate AU, SAM guidelines suggest that a multi-disciplinary team of health professionals be available to assist in the management of young people in hospital.[10]

SAM research suggests that over the last decade, adolescent health care in the USA has witnessed a welcome increase in integration of services, increased general understanding about adolescent development, increased focus at national level regarding the needs of youth, and a substantial increase in the development and testing of useful interventions in youth health. However, key national adolescent health figure also believe that a continued deterioration of support systems, changes in family structure, economic upheaval, and a lack of recognition of changes occurring in lives of modern day youth have seriously negatively impacted on the health of American young people. The care of chronically ill adolescents, training of health professionals in adolescent care, and the development of adolescent health databases at local state and national levels are among the key issues SAM believes need increased attention in the next decade.[11]

We believe that the goals contained in the SAM guidelines for the care of young people in managed care are relevant to all levels of today's NHS including hospital services. The four suggested key goals are:

1. that young people have full access to comprehensive coordinated care throughout adolescence and into adult life
2. that managed care must be structured to ensure access to age-appropriate and adolescent-focused services [9]
3. that health care financing systems must be adequate to support necessary systems of care
4. the managed care organisations must develop quality goals and indicators that are adolescent specific

Other suggested goals include:

1. organisations should require adolescent specific proficiency among providers
2. continuity of health insurance past 18 years to ensure efficient transition to adult health care
3. managed care should include periodic preventive health screening - including family planning, pregnancy-related care, sexually-transmitted diseases, immunisations, drug & alcohol issues, mental health
4. services must be culturally and linguistically sensitive services
5. services must be coordinated with good access for marginalised young people
6. those responsible for authorisation and utilisation review must have some adolescent -specific experience/training

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# EXISTING DATA
## ON ADOLESCENT HOSPITAL USE AND NEED

Aside from the data to be presented in Section on Adolescent Bed Usage, little information exists on the use of hospital services by young people. Estimates of bed need come from a recent detailed published study of one region (Oxfordshire)[1], older general data from England and Scotland[2] and from unpublished 1974 data from the South West Regional HA.

The most influential estimate of adolescent bed usage has come from the British Paediatric Association (BPA) report of 1985, which used now dated 1981-2 data from England and from Scotland to estimate that 7.5 beds per 100 000 population were required for young people aged 11 to 15 years,[3] leading the BPA to suggest that 15 adolescent beds were needed for each DGH serving around 250 000 population. (See Table 1).

*Table 1.*
*Daily beds occupied by age in England and Scotland (excluding psychiatry and obstetrics), 1983 (from BPA, 1985:10-11)*

| | 10-14 years | 15-19 years | TOTAL |
|---|---|---|---|
| England: daily beds occupied per 100,000 persons | 5.28 | 7.24 | 12.52 |
| | **11-15 years** | **16-18 years** | **TOTAL** |
| Scotland: daily beds occupied per 100,000 persons | 5.52 | 4.72 | 10.24 |

Figures from the South West Regional HA from 1974 showed that adolescents occupied an average of 21 bed days for each 600,000 population, being 8.75 beds per 250 000 persons, although the ages in question were not stated.

Occupancy data from existing AU is also valuable. Data from one of the three standalone teenage wards in the country showed that a 19 bed ward in a hospital serving a population of 300 000 persons showed occupancy rates of 76-86% confirming the estimate of a need for 15 beds per 250 000 persons.[4]

Information on admission rates for young people is also limited. The only available information comes from a regional study in Oxfordshire from 1979-86 which showed that admission rates ranged from 740 to 1100 per 10 000 persons during the years 12 to 19 years. Peak admission rates were at 18 and 19 years of age, largely for trauma and orthopaedic admissions.

*Table 2.*
*Admission rates per 10,000 people at each age by sex for all specialities excluding mental health and obstetrics, Oxfordshire 1979-81.*
*(from Henderson et al., 1993)*

| | 12 years | 13 years | 14 years | 15 years | 16 years | 17 years | 18 years | 19 years |
|---|---|---|---|---|---|---|---|---|
| **Male** | 420.1 | 403.7 | 418.7 | 365.5 | 363.8 | 417.1 | 437.4 | 435.7 |
| **Female** | 318.8 | 333.1 | 379.4 | 435.3 | 498.8 | 563.8 | 620.5 | 660.3 |
| **Total** | 738.9 | 736.8 | 798.1 | 800.8 | 861.6 | 980.9 | 1057.9 | 1096.0 |

## NUMBER OF ADOLESCENTS IN GENERAL HOSPITALS

Other information on adolescent bed usage comes from estimates of the proportion of adolescents in children's and general hospitals. A survey by the King's Fund in 1953 showed that adolescents (age unspecified) occupied around 9% of 3954 beds in 195 wards in England and Wales,[5] a figure identical to that for adolescents (12-20 years) to general hospitals in Great Glasgow Health Board area in 1990.[6]

Data from the USA provides a lower estimate. A survey of 400 acute hospitals showed that 5% of 33.4 million hospital discharges for 1987 were for adolescents aged 10-18 years.[7]

## NUMBER OF ADOLESCENTS IN GENERAL HOSPITALS

Adolescents comprise similar proportions of children's hospital admissions. Young people 12-19 years made up 9% of total admissions to the Royal Hospital for Sick Children in Glasgow in 1990,[6] and 10% of admissions to the Royal Children's Hospital, Melbourne, in 1978.[8] More recent figures from the tertiary Great Ormond Street Hospital for Children show that young people over 13 years made up 12.8% of bed activity in 1996-97 (R. Viner, personal communication).

## LENGTH OF STAY

No British exists on the length of stay of young people in hospital. The large 1987 USA study showed that adolescents 10-18 years had an average hospital stay of 5.2 bed-days, less than the average of 6.4 bed-days for all patients.[7]

## GENDER

No UK data is available on the sex distribution of young people in hospital. The national USA study of discharges for 1987 found that boys made up 54% of discharges at 10-14 years decreasing to 34% at 15-18 years and 22% at 19-24 years.[7]

## WHERE ADOLESCENTS ARE NURSED

Extremely little information is available on where in hospitals adolescents are nursed. NAWCH estimated in 1990 that 80% of young people were nursed inappropriately in adult wards, although evidence for this was not presented.[9] Data from the South West Regional HA from 1976 showed that 58% of 12-16 year old adolescents were nursed in open adult wards, 17% in single rooms on adult wards, and 25% in the children's ward.[3]

## ADMISSIONS BY SPECIALITY

Limited information is available on the breakdown of specialities to which young people are admitted. Unsourced data for the South West Regional HA from the mid 1980s showed that 46% of young people aged 11-18 years were admitted for general and orthopaedic surgery, 27% for medical illnesses (i.e. paediatrics or general medicine), 10% for ENT, and 5% for plastics, thoracic surgery and neurosurgery.[9] Further unsourced data from the same HA from the early 1980's, reported that 25% of patients were medical or paediatric, 25% orthopaedic, 15% general surgery, and 10% ear nose and throat.[10] Information from a recent USA survey of 25 AU confirms that the major users of AU beds were the medical (60%) and surgical (28%) services.[11]

## REHOSPITALISATION

No UK data is available on readmission rates for hospitalised young people. An Irish study of 120 adolescents in a children's hospital found that around 70% adolescents admitted had had previous hospitalisations.[12]

## OUTPATIENTS

No published information is available on outpatient usage and attendances by young people in the UK.

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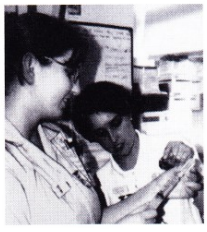

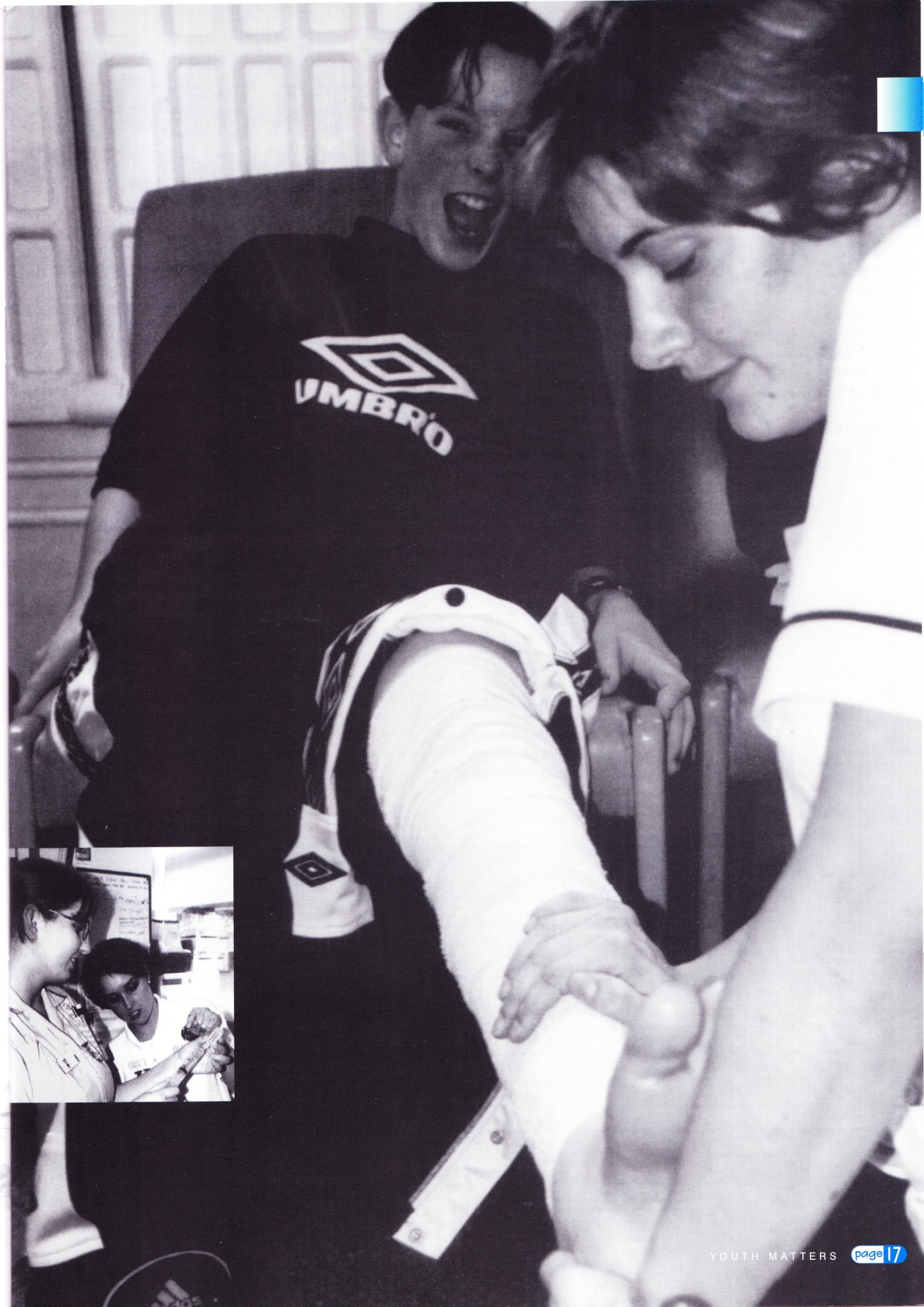
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# RESEARCH STAGE I

## ADOLESCENTS IN HOSPITAL IN THE UNITED KINGDOM: A SURVEY OF BED USAGE AND PURCHASER SPECIFICATIONS

As noted in the Introduction, little data is available on hospital bed usage by adolescents in the UK[1] and no information is available on the extent to which health authorities and boards in the UK attempt to meet the needs of adolescents in hospital. The aims of this stage of the study were to assess the nature of specifications for adolescent health by authorities and boards in the UK, to identify adolescent units presently existing, and to determine the number of beds needed for adolescents in district general and teaching hospitals.

### METHODS

*Stage 1a.*

Data on purchaser specifications and adolescent facilities within HA was gathered by a questionnaire mailed in August 1997 to the chief executive of each of the 124 health authorities and boards in the United Kingdom. Questionnaires were filled out by chief executives (rarely) and (more commonly) consultants in public health or those responsible for commissioning children's and young people's health. The response rate for completed questionnaires was 90.3%.

The questionnaire asked HA the following questions:

1. Does your authority specify any particular needs of adolescents separately from children within its service specifications, particularly in relation to secondary and tertiary care?

**1a.** If yes, would you please copy any relevant service specification for us?

**1b.** If no, do you have any plans to specify these in the future, or do you have any other comments

2. Are you aware of any specific provision for adolescents in relation to secondary and tertiary care with your authority?

Although physical health (i.e. medical and surgical care) was the focus of this survey, the HA were also requested to provide information on adolescent mental health specifications and facilities.

*Stage 1b.*

Data on bed usage by adolescents in Britain was subsequently requested from one large HA (over 500 000 persons if possible) in each region of England and in Scotland and Wales that had responded to the original survey. 5 HA responded with the appropriate data. The HA was asked to provide figures on bed occupancy in the 1997-98 year by adolescents 12 to 19 years inclusive who were resident in that HA. Data was requested for each single year band within the age range, split by sex and by speciality (excluding obstetrics and mental health). Bed need is calculated in terms of a standard UK DGH serving approximately 250 000 persons.

### RESULTS

Response rate by region and details of adolescent physical health specifications are given in Table 1 and mental health specifications in Table 2.

*Table 1.*
*Adolescent physical health specifications*

| Region | No. of HA in Region | Response (%) | Adolescent physical health specifications (%) | | | |
|---|---|---|---|---|---|---|
| | | | Specific to Adolescents | Part of Child Health Specifications | Specifications : no details | No specifications |
| Anglia & Oxford | 9 | 8 (88.9) | 1 (12.5) | 0 | 0 | 7 (87.5) |
| North Thames | 14 | 13 (92.9) | 2 (15.4) | 0 | 0 | 11 (84.6) |
| North West | 16 | 13 (81.3) | 2 (15.4) | 0 | 0 | 11 (84.6) |
| Northern & Yorkshire | 13 | 13 (100) | 0 | 1 (7.7) | 0 | 12 (92.3) |
| South Thames | 12 | 10 (83.3) | 0 | 0 | 0 | 10 (100) |
| South & West | 12 | 11 (91.7) | 4 (36.4) | 1 (9.1) | 0 | 6 (54.5) |
| Trent | 11 | 11 (100) | 1 (9.1) | 0 | 0 | 10 (90.9) |
| West Midlands | 13 | 11 (84.6) | 0 | 2 (18.2) | 1 (9.1) | 8 (72.7) |
| Scotland | 15 | 14 (93.3) | 0 | 2 (14.3) | 2 (14.3) | 10 (71.4) |
| Wales | 5 | 5 (100) | 0 | 1 (20) | 0 | 4 (80) |
| Northern Ireland | 4 | 3 (75) | 1 (33.3) | 0 | 0 | 2 (66.7) |
| TOTAL | 124 | 112 (90.3) | 11 (9.8) | (7 (6.3) | 3 (2.7) | 91 (81.3) |

Only 9.8% of HA had specifications for the management of the physical health of adolescents in hospital, with another 6.3% including some specifications for adolescent care in their child health specifications. The specific commissioning guidelines from the 11 HA are given in Table 3. Guidelines ranged from simple directives to providers to follow "best practice" in adolescent care to larger documents providing clear guidance on the needs of adolescents in hospital (3HA only). There was considerable regional variation, ranging from no HA with specifications in South Thames region to 45.5% in the South and West region.

*Table 3.*
*Details of specifications in 11 HA with specific policies for adolescent care*

| REGION OF HA | GUIDELINES |
|---|---|
| Anglia & Oxford | Separate services for adolescents will be provided and will include kitchen facilities and social space. Privacy, the involvement of young people in their own treatment and consideration of transition are important issues. |
| Northern Ireland | "Developing services for adolescents with chronic health problems" is listed as one of 6 Purchasing Priorities for Child Health Services |
| North Thames | No details provided |
| North Thames | Service specifications require the needs of adolescents to be addressed separately either in a dedicated AU or in separate facilities on children's wards |
| North West | A document "The Needs of Adolescents in Hospital" has been developed as part of the service specifications for both local and specialist child health services. The document specifies a separate ward for young people in hospital or the provision of separate bays on children's ward if a ward is not possible. Privacy and involvement in treatment decisions are flagged as key issues. |
| North West | Providers are simply required to note best practice for adolescents |
| South & West | Providers are asked to provide separate inpatient facilities for adolescents |
| South & West | An "Adolescent's Charter" is included in specifications, including sections on privacy, involvement in treatment decisions and consent issues. |
| South West | Providers are asked to develop an adolescent medical and surgical unit for those over 11 years, either as a free standing unit or as part of one general children's ward |
| Trent | Specifications include a document "Care of Young People in Acute Hospitals: Policy & Specifications" which includes extensive specifications regarding specific bed provision, the provision of social and recreational space, kitchen and other facilities, and notes the importance of issues of consent, involvement in treatment and the special developmental needs of young people. |

*Table 2.*
*Adolescent mental health specifications.*

| REGION | DISCRETE SPECIFICATIONS | NO SPECIFICATIONS | UNKNOWN |
|---|---|---|---|
| Anglia & Oxford | 3 (37.5) | 5 (62.5) | 0 |
| North Thames | 5 (38.5) | 8 (61.5) | 0 |
| North West | 2 (15.4) | 10 (76.9) | 0 |
| Northern & Yorkshire | 6 (46.2) | 7 (53.8) | 0 |
| South Thames | 4 (40) | 6 (60) | 0 |
| South & West | 8 (72.7) | 2 (18.2) | 1 (9.1) |
| Trent | 6 (54.5) | 4 (36.4) | 1 (9.1) |
| West Midlands | 4 (36.4) | 7 (63.6) | 0 |
| Scotland | 4 (28.6) | 10 (71.4) | 0 |
| Wales | 1 (20) | 4 (80) | 0 |
| Northern Ireland | 2 (66.7) | 1 (33.3) | 0 |
| **TOTAL** | **45 (40.2)** | **64 (57.1)** | **3 (2.7)** |

The percentage of HA with specifications for providing adolescent mental health services is shown in Table 2. Overall, 40.2% of HA reported having specifications for providing adolescent mental health facilities, ranging from 15% in the North West region to 73% in the South and West region.

Nine HA (8%) reported having a dedicated adolescent medical or surgical ward within one of their provider Trusts. An additional 16 HA (14.2%) reported that provider Trust(s) contained facilities for adolescents on their children's wards. 20 HA (17.9%) contained an adolescent mental health facility.

## BED USAGE

Adolescent bed day usage by age and sex in 5 large HA in England is shown in Appendix A. An estimate of the beds occupied by adolescents of each age assuming 80% bed occupancy is shown in Table 4. Day cases have been counted as 1 bed day.

*Table 4*
*Number of beds used by adolescents per year assuming 80% occupancy, by HA in 1997-1998*

| HA & population | 12 years | | 13 years | | 14 years | | 15 years | | 16 years | | 17 years | | 18 years | | 19 years | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Raw HA data | Estimate for 250,000 population | Raw HA data | Estimate for 250,000 population | Raw HA data | Estimate for 250,000 population | Raw HA data | Estimate for 250,000 population | Raw HA data | Estimate for 250,000 population | Raw HA data | Estimate for 250,000 population | Raw HA data | Estimate for 250,000 population | Raw HA data | Estimate for 250,000 population |
| Buckinghamshire 660000 | 3.16 | 1.20 | 3.23 | 1.22 | 3.08 | 1.17 | 4.15 | 1.57 | 4.02 | 1.52 | 3.94 | 1.49 | 5.68 | 2.15 | 3.88 | 1.47 |
| East London & City 608235 | 3.51 | 1.44 | 7.51 | 3.09 | 7.48 | 3.07 | 10.07 | 4.14 | 6.29 | 2.59 | 11.88 | 4.88 | 13.82 | 5.68 | 8.29 | 3.41 |
| North Yorkshire 726000 | 3.04 | 1.05 | 2.42 | 0.83 | 2.50 | 0.86 | 3.15 | 1.08 | 3.33 | 1.15 | 4.62 | 1.59 | 6.13 | 2.11 | 6.89 | 2.37 |
| Avon 970000 | 4.59 | 1.18 | 5.17 | 1.33 | 5.99 | 1.54 | 5.77 | 1.49 | 6.31 | 1.63 | 6.62 | 1.71 | 6.58 | 1.70 | 6.86 | 1.77 |
| Birmingham HA 1008000 | 7.08 | 1.76 | 7.57 | 1.88 | 9.83 | 2.44 | 9.87 | 2.45 | 9.02 | 2.24 | 9.03 | 2.24 | 9.76 | 2.42 | 9.52 | 2.36 |
| **Average bed usage per 250,000 population** | | 1.33 | | 1.67 | | 1.82 | | 2.15 | | 1.82 | | 2.38 | | 2.81 | | 2.28 |

Table 4 shows that the calculated bed need for young people aged 12 to 19 years inclusive is 16.26 beds for each 250 000 of the general population. For adolescents aged 12 to 18 years, the calculated bed needs is 13.98 beds per 250 000.

## DISCUSSION

Almost thirty years after Platt first drew attention to the special needs of adolescents in hospital,[2] only around 10% of commissioning authorities in the United Kingdom recognise the specific health needs of this group of general hospitals. Even more concerningly given the recent emphasis on commissioning young people's mental health,[3] only 40% of HA have specific guidelines for their specific mental health needs.

This is the first survey of the commissioning of adolescent secondary and tertiary care. The response rates in each region were excellent and sufficient to be confident in the results of the survey. Regional variations were great, and suggest that this reflects local interest; the region with the highest proportion of HA with adolescent specifications (both physical and mental health) was the South and West region, reflecting the work undertaken locally done with young people in Portsmouth.

The calculations of bed need for young people in the 5 HA suggest that an AU of around 15 beds is the appropriate size for a DGH serving 250 000 persons. While there were variations between the bed need for the 5 HA listed, in each case an AU around 14-17 beds would have been necessary to house the adolescents of 12 to 18-19 years admitted in each DGH.

This estimate agrees well with that of 15 beds per 250 000 persons published by the BPA in 1985.4. This is perhaps somewhat surprising given the reduction in paediatric bed usage over the past two decades.[5] However, it may reflect the lack of improvement in adolescent morbidity and mortality over the last twenty years.[6]

Both obstetrics and mental health were excluded from these calculations as authorities agree that obstetric adolescent patients are best treated in regular obstetric units, albeit with special provision for their needs. Mental health was also excluded from the calculations. No effort was made in this study to estimate bed need for adolescent mental health units as present bed usage does not equate with actual need i.e. unlike physical health where adolescents are easily if inappropriately housed on paediatric or adult wards, adolescents requiring psychiatric admission are likely to be managed as outpatients if not dedicated adolescent beds are available.

Existing facilities for young people in hospital were poor, with only 8% of HA having any dedicated adolescent facilities and a further 14% providing facilities within their children's ward. This is unacceptably poor given the calculation that moderate sized DGHs would have about 15 beds of adolescent activity. The observation that only 18% of HA contained an adolescent mental health reflect the parlous state of adolescent mental health provision in the UK.

It should be noted that this survey did not address providers both within and outside the NHS, some of whom will have developed their own specifications and policies on adolescent health.

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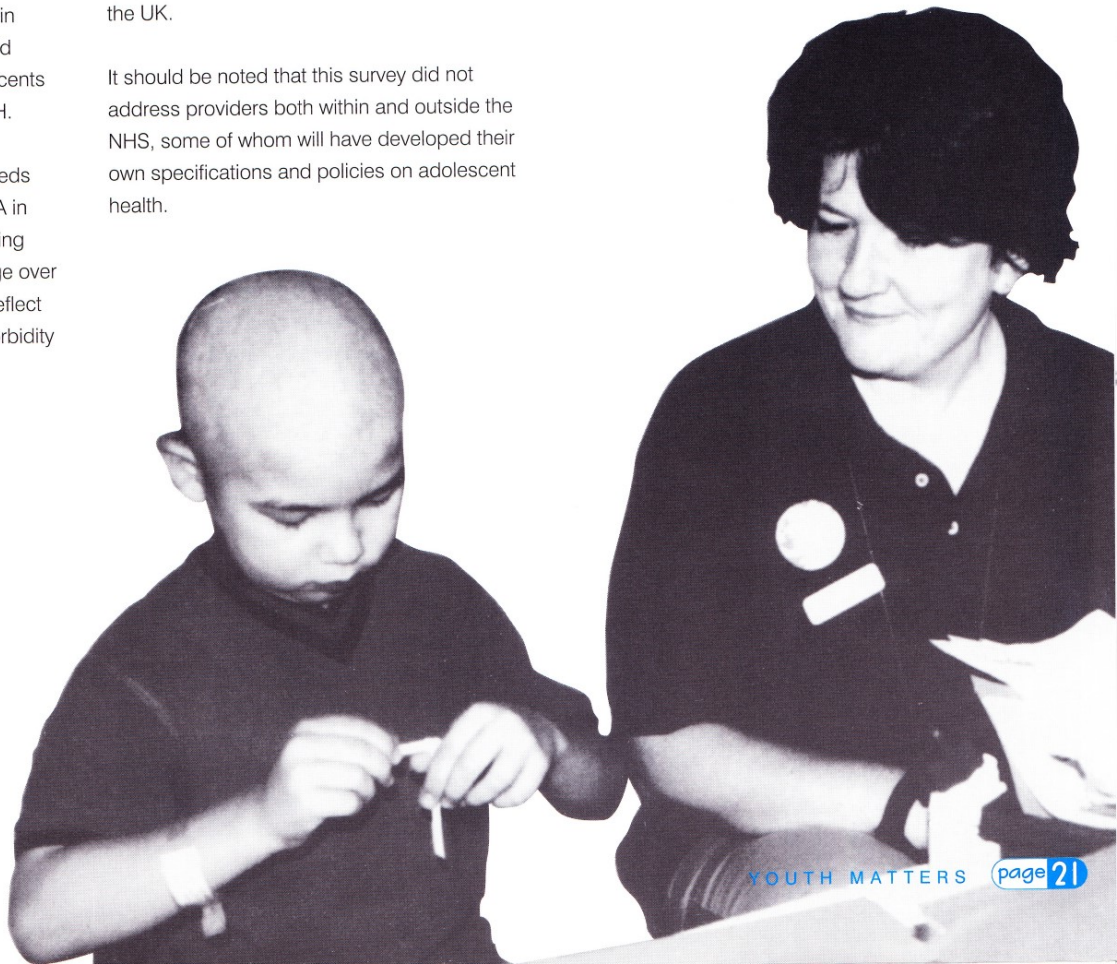

# RESEARCH STAGE II

## SYSTEMATISED REVIEW OF THE LITERATURE

*"No longer children but not yet adults, adolescents may be the most perplexing patients you have to deal with. Just how should you approach them? Should you give them their own private rooms or integrate them with the rest of the patients? Should you "lay down the laws" or treat them with kid gloves? Should you tell them about death on the floor or try to hide the fact from them? Answers to such questions don't come easily, of course. In every case, you have to make decisions based on your assessment of the individual patient. But people who have worked on youth wards in hospital have found a few approaches that are generally effective-and that may help you make such determinations."*

Despite the lack of guidelines for the care of hospitalised young people, an extensive literature does exist on the needs of adolescents in hospital. However, the literature is fragmented and not easily accessible. Little has been published within the medical literature, with the largest proportion of studies coming from the nursing,[23] and allied health literatures.[4] Others can be found in the sociological or psychological literatures, or are confined to obscure publications. Others have never been formally published. In particular, information on the function of allied health professionals (such as Psychologists and Psychotherapists, Social Workers, Occupational Therapists, and Youth Workers) in adolescent care is scattered throughout the literature of each discipline - literatures that are often not available through standard computerised database searching.

The existing literature requires systematic review in order to produce guidelines for purchasers, commissioning groups, and providers in the development of dedicated adolescent inpatient services in the NHS.

*Objectives of the review*

**A.** to review published and unpublished research on the specific needs of hospitalised adolescents.

This included review and synthesis of all information on:

1. the need for specific inpatient facilities for adolescent patients
2. the physical environment of adolescent units i.e. planning and design of the physical space of the unit
3. the social environment of the unit i.e. activities and peer group work
4. the therapeutic environment and function of the unit i.e. the disciplines required in a multi-disciplinary adolescent team and the models of care appropriate to the adolescent setting
5. data available on adolescent expectations and desires regarding inpatient facilities
6. data available on the economic requirements and consequences of adolescent inpatient facilities

**B.** development of guidelines for purchasers/commissioners and providers on the provision of adolescent inpatient facilities

*Methodology*

The review process drew upon the standard methodology for the performance of Systematic Reviews. Systematic Reviews were originally developed for the analysis of randomised controlled clinical trial data. However, the methodology's emphasis on the inclusion of unpublished and difficult to access data, hand-searching of references, non-English publications, and objective reviewer assessment of publications, has also proved useful in other health related areas. 123 articles were found that fitted the review criteria. Methodology is discussed in Appendix B.

The results of the systematic review are presented in the following sections.

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# THE DEDICATED AU

## ARGUMENTS FOR A DEDICATED ADOLESCENT UNIT

*"the frequent practice of regarding older teenagers as adults and younger ones as children, scattering them about on adult and paediatric wards according to their disability or assigned service, with an arbitrary and developmentally inconsistent age division, is to be condemned"*

*"The design, policies, schedules and systems (of hospitals) are developed more for the convenience of the physician and other health-care team members than for consumer or patient. Adolescents, as naive health care consumers, will usually feel uncomfortable, fearful and distrustful in this environment."*

The published literature over-whelmingly supports the establishment of dedicated and free -standing adolescent units where-ever possible.[1,3-30]

The USA Society for Adolescent Medicine (SAM) strongly supports the establishment of dedicated AU in children's and general hospitals[16] as does the Royal College of Paediatrics and Child Health.[11] SAM guidelines suggest that an AU is the "optimal approach" to the delivery of developmentally appropriate health care to hospitalised young people.[16]

Nurses in the UK have supported the establishment of dedicated AU since 1953.[31]

Young people themselves are over-whelmingly in favor of dedicated adolescent health services. An Irish survey of 120 hospitalised young people found that 99% wished to be nursed with other young people, that no adolescents wished to be nursed on children's wards and that only 2% wished to be in an adult facility.[35] A recent UK survey showed that 85% of adolescents believe that dedicated adolescent services are needed because present health services are difficult to access and are not focused on youth health issues.

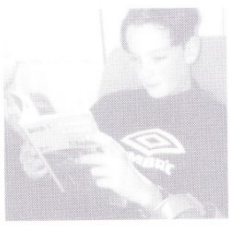
The arguments for a dedicated AU that meets the psychosocial needs of adolescents are as follows:

- the psychosocial and development needs of young people are very different to those of children or adults, and are unlikely to be met in children's or adult wards[11,16,36]
- the common needs of adolescence unite sick young people more than the particular needs of their diseases separate them[11,37]
- hospitalisation can delay fulfilment of the tasks of adolescence e.g. it may increase dependence on parents and staff at a time when the adolescent is struggling for independence.[18]
- adolescents may feel uncomfortable, fearful and distrustful in an environment that is designed to meet the needs of doctors and nurses (i.e. diseases or speciality-based wards) rather than those of young people[2]
- there is good evidence that reduction in anxiety facilities post-operative pain relief and post-surgical health outcomes[38,39]
- AU provide necessary training for staff from many disciplines in adolescent medicine and give professionals working with young people an increased sense of professional identity and credibility[32] Improved training of medical and nursing staff in dealing with young people will improve adolescent health outcomes[40]
- multi-disciplinary health care is most easily provided in a multi-speciality unit dedicated to the care of a type of patient rather than a type of illness[25]
- only adolescent units deal adequately with educational, social and vocational issues necessary to ensure adolescents make the transition to independent adult living
- the grouping of adolescent patients together facilitate the development of expertise in adolescent medicine and health, and makes possible research into border issues of illness in adolescence
- young people strongly support separate dedicated facilities (see above)

### ARGUMENTS AGAINST HAVING DEDICATED ADOLESCENT UNITS

Arguments against having dedicated adolescent inpatient units have been advanced. Such arguments are not convincing (see Table 1)





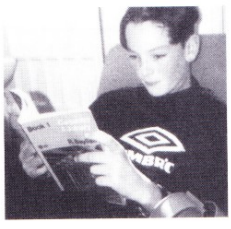


*Table 1.*

| Argument | Rebuttal |
|---|---|
| 1. adolescents are a small proportion of the total patients in general hospitals and therefore no special arrangements should be made for them[21] | Bed-usage figures show that young people make up around 5-7% of DGH admissions - a similar figure to that children who have special wards. (See Section on Bed Usage) |
| 2. the particular nursing demands of specialities outweigh the general commonality of adolescence | This may be true of some very technological specialities e.g. intensive care and neurosurgery etc.[16] However, the common needs of adolescence unite sick young people more than the particular needs of their diseases separate them[11,12,37] |
| 3. grouping adolescents together threatens medical management and reduces continuity of care by junior medical staff[32] | The multi- speciality AU improves quality of care by attending to the psychological and social needs of the patient as well as the medical ones. Medical continuity is easily achieved by ensuring easy access for junior medical staff from all specialities |
| 4. the loss of adolescent patients may threaten the viability of separate wards for some specialist services[12] | The needs of providers and medical staff cannot take precedence over demonstrated patient need |
| 5. AU are places only for disturbed adolescents, and suffer severe disciplinary problems[32,41] | Behavioral problems with adolescents occur on all wards - particularly general and children's wards where staff are not trained in dealing with adolescent behaviour and problems. |

We believe that the arguments for a dedicated AU are convincing. Providers must now answer the question "Why not have a bed care unit for adolescents?"[36]

## SPECIFIC DISEASE UNITS

A number of disease-specific adolescent units have been set up both in North America and Britain, catering for cancer,[42] cystic fibrosis and orthopaedics. There is no published information available on the development of specialized AU, although information can be obtained on teenage cancer units from the Teenage Cancer Trust, London.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