

Making It Better: For Children and Young People

Clinical case for change

*Report by Sheila Shribman, National Clinical Director
for Children, Young People and Maternity Services*

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Making It Better: For Children and Young People

Providing the best services is the major driving force behind service changes according to Sheila Shribman, National Clinical Director for Children, Young People and Maternity Services.

The need for change

At the age of three I was in hospital for many weeks as I was seriously ill with scarlet fever. I can still remember how upset and anxious I was at that time because my parents were only allowed to visit me once a week, which also caused them considerable distress as well.

Thankfully, the NHS now recognises the different needs of children and young people. Visits are no longer restricted and clinically we have stopped treating them as small adults.

The results have been dramatic. By constantly changing the way we provide services and taking on new ideas, we have improved the health of our children and young people.

Technology and advances in medical science have significantly increased the number of children surviving serious illness and living with disabilities. For example, deaths from congenital heart disease, once greatest in infancy, are now higher in adults. Today, around 75% of children with congenital heart disease survive to adulthood and adult services have had to change as a result.

Children with cancer have benefitted enormously in recent years from treatment in specialist centres by teams of specially trained experts, working in partnership with local services. Outcomes have improved dramatically as a result of this sub-specialisation and collaborative research. When I was a trainee doctor most children with cancer died. By the mid-1990s, nearly 75 per cent of children with cancer survived at least five years after diagnosis (known as five-year survival). For the main type of childhood leukaemia, five-year survival is now above 80 per cent, and exceeds 50 per cent for every main type of childhood cancer.

To achieve this, families have had to travel further for care for their child, but I have never met a parent who was not prepared to do this if it meant better treatment. However, even in

Benefits of reform for children and families

1. Improved clinical outcomes
2. Improved experience and environment
3. Child and family-centred approach
4. More say in their care
5. Workforce with appropriate skills and experience
6. Ensure safety, quality and sustainability

this area of success, more change is needed to improve services even further, especially to meet the needs of young people as well as babies and children. Therefore further reorganisation will be required of highly specialised services as well as local ones.

Prevention, not just treatment

Since the 1950s, advances such as immunisation have systematically reduced the number of deaths and the complications suffered by children and young people. In the 1950s, there were over 600,000 cases of measles annually in England and Wales and over 150,000 notifications of whooping cough per year. Now whooping cough is far less common and measles is only ever seen in areas where the immunisation rate is reduced.

What we and parents know is that 80% of all illnesses in childhood are managed by families at home. However in a typical year, a pre-school child will see a general practitioner about half a dozen times, while a child of school age will visit the practice two or three times. A quarter of the calls to NHS Direct involve children. Up to half of infants aged under 12 months and one quarter of older children will attend an accident and emergency department annually so the health service is providing lots of advice, support and care.

In any one year, one in 11 children will be referred to a hospital outpatients clinic, and one in 10 to 15 will be admitted to hospital. The majority of children's admissions to hospital including a significant amount of surgery in childhood, is unplanned.

We treasure our local hospitals in England. We rely on them and believe they are the best way to provide care. The reassurance they provide seems particularly welcome when children fall ill, but when you are looking after sick children the most important factor is skill and experience, not necessarily distance.

Meningitis is the classic case. Without knowledge and experience it is easy to misdiagnose. The NHS has to have services that effectively triage children with suspected meningitis and ensure they get the right attention by staff with the right skills who can get further specialist advice when needed. A study in 2005 found that inadequate care in the identification and treatment of children with meningococcal disease significantly reduced the likelihood of survival.

Children's Services 1948 – No specialist consultants, no children's wards, low-level of immunisation, high infant mortality, no attention to chronic healthcare or social influences, major inequalities, children seen as small adults.

Children's Services 2007 – Children's centres, children's community nurses, separate wards for children and teenagers, high levels of immunisation, low infant mortality, specialist hospital facilities and staff for children.

New Models of Children's Networks

- Neo-natal intensive care
- Paediatric intensive care
- Children's cancer services
- Children's surgical care
- Palliative care
- Safeguarding children

If a child is unwell a parent should consult their GP or NHS Direct for advice. If they believe their child has meningitis based on their knowledge of the symptoms and signs urgent assessment at a hospital is needed.

That does not mean we need paediatric intensive care or inpatient facilities in every hospital. It is about the service and the staff. Paediatric intensive care requires sophisticated equipment, trained specialist staff and easy access to a wide range of support and other services such as paediatric pathology and radiology. There is also a requirement for appropriate child-friendly facilities and accommodation for families.

Concentrating skills and expertise in larger centres allows staff to retain and develop their knowledge and skills. But staff in other services, including local A&Es, health centres, GP practices and ambulance trusts, need paediatric skills so that all staff who could be involved in the care of a child are able to recognise a critically sick or injured child and initiate appropriate immediate treatment including resuscitation and stabilisation. Prompt transfer by ambulance when needed is an essential component of any plans for children's services.

Meningitis is an example of where improvement in early intervention and prevention have also led to an improvement in outcomes. Awareness campaigns have helped parents and those most at risk, such as students, to identify symptoms and seek help early. The introduction of immunisation against some types have all helped, but the need for vigilance remains.

If a child does have to be admitted to hospital they should be treated in an appropriate environment and this will differ depending on their age and stage of development. Adolescents have different needs to young children. Over the past 30 years or so the number of children admitted to hospital has more than doubled, but the average length of stay has reduced from 8 to 2 days. On the whole, children's best interests are served by being in hospital for the briefest time needed to provide safe, effective treatment.

This is not exclusive to physical illnesses. Children or young people who require admission to hospital for mental health care need to be treated in an environment suitable for their age and development. This means that children should no longer be treated in adult psychiatric wards but in specialist CAMHS (Children and Adolescent Mental Health Services) units unless for reasons of maturity and independence they prefer to be admitted to a ward specialising in treating young adults.

Local where possible, specialist where necessary

The solution for services is a network of care which ensures that children receive assessment and any treatment that is needed in the most appropriate place and are then returned home with support as soon as possible. This will allow for a concentration of skills, ensuring there is 24-hour access to the right consultants with the best diagnostic equipment and

techniques. This will mean fewer, smaller in-patient services, some extended ones, together with improved and expanded community services. This is not always the cheaper option.

This shift is already occurring in children's surgery. Local district general hospitals currently deliver 60% of children's surgery (more than 540,000 procedures a year). However, this has been falling over the last 10 years, from 76% in 1994-5, reflecting the trend towards more children's surgery being undertaken in specialist paediatric centres with better results.

But general surgeons also need to maintain their skills in dealing with children for emergency or urgent circumstances. The provision of a children's surgical service should therefore be part of a network of care, so that general and specialist health organisations work together to best configure services and ensure there is appropriate and skilled capacity to meet the needs of their local communities, without wasteful duplication or competition for scarce specialist staff. For children with serious or uncommon problems this will mean travelling to get the best care, but the result will be access to highly skilled staff, ensuring the right treatment and a better chance of recovery.

Urologists, those that specialise in the treatment of problems with the urinary tract, are a scarce resource, especially those that specialise in the treatment of children. In Portsmouth and Southampton a network has been established to deliver specialist urology care as near to home as is safe and practical. A paediatric urologist, based in Southampton, carries out specialised urological surgery, including cancer surgery, for the Wessex region. Patients requiring such surgery travel to Southampton. Over in Portsmouth, adult urologists hold regular children's clinics and if appropriate operate on some cases as day cases locally. The paediatric specialist visits Portsmouth regularly to carry out more complex surgery that requires a stay in hospital and also provides a clinic to see new referrals and follow ups to prevent patients from having to travel even further.

To develop the skills and expertise trainees spend 6 months in the paediatric urology department in Southampton. The department at Portsmouth has particular expertise in lithotripsy in adults (fragmenting kidney stones using energy waves not surgery). Because stones in children that require this treatment are rare, they are referred to Portsmouth where the paediatric urologist can carry out the procedure alongside an adult urologist expert in this field. The team are now looking to expand this service further by setting up an operating session in Dorchester. By working together across the region in this way different hospitals are providing better care to children.

Living, not just surviving

For a child with a long term condition such as asthma, a large amount of their treatment and care should be provided in the community with the aim of allowing their illness to be managed in such a way that enables them to do their usual activities at home, school or socially. Children's community teams, particularly children's trained nurses, can work with families, linking in with other services (in primary and secondary care), to help prevent hospital admission and facilitate early discharge if a child has to be admitted to hospital.

During the 1990s there was a fall of over 40% in hospital admissions for asthma even though the number of children under 5 treated for asthma overall actually increased. This result has occurred through better treatment, but there is still a long way to go to achieve the best we can.

If a child does experience a more acute episode or recurrent problems then they, and their parents or carers, can decide based on their knowledge of the illness and their asthma action plan, what they need to do provided they have been well informed and given the right opportunities to learn about the disease.

This changing pattern of children's and young people's health needs and what we can now offer them requires a new approach.

Much greater support is needed for looking after all children at home or closer to home, for example by providing new preventative services through children's centres and addressing the needs of adolescents more effectively.

There are some conditions such as diabetes which are becoming increasingly common in childhood. Its incidence has doubled in the last 20 years. This disease imposes a severe toll on sufferers by reducing average life expectancy by 23 years in type 1 diabetes (insulin dependent). Type 1 diabetes is increasing in all age groups, but particularly in under-fives and young people and the average age of diagnosis is between 10 and 14 years. Caring for children and young people with diabetes is fundamentally different from providing services for adults. It is a complex process that must be firmly focused on the child and their family, supported by a wide range of healthcare professionals working as a team taking account of the medical aspects in the context of the child's life and the need for normal day-to-day

Jo's story

Jo was diagnosed at birth with a rare heart and breathing condition. She spent the first 5 months of her life in the cardiac unit and several months in the paediatric intensive care unit. Her condition required her to be fed through a drip and then a tube in her nose and long periods of sedation, on a ventilator.

When she was ready the team involved in her care started planning her discharge, supporting and training her parents so she could be looked after at home. They were provided with the necessary equipment and support from community based nurses with special skills in caring for children. Jo is doing well at home, still on her ventilator but having a more normal life – visiting the shops and playing with her brother and sister.

activities eg school. Evidence suggests that diabetes control in children and young people is unsatisfactory and changes are needed.

Children with less common diseases such as Cystic Fibrosis are living much longer, and in better health, but they still need care from a range of staff and their families need support. Services for children with Sickle Cell disease need to be developed following the recent introduction of the new screening programme, as do children with deafness who are also being diagnosed as babies.

But if we expect parents and children to travel for specialist care, we need to reassure them that the appropriate aftercare and support will be available locally. That means children's community nursing services, access to physiotherapy and other support services such as good social care and continued educational opportunities.

Children and young people with life-limiting conditions now have longer life expectancy and a better quality of life due to improved treatment and support. The 2002/4 family resources survey estimated that there were approximately 700,000 disabled children under 16 in Great Britain. In the past 10 years, the prevalence of severe disability and complex needs has risen. This is due to a number of factors, including increased survival of preterm babies and children after severe trauma or illness. There are up to 6000 children living at home who are dependent on assistive technology.

A third of parents with a severely disabled child under two years old use more than three pieces of equipment daily to provide basic care. Four out of five 12 to 14 year-old severely disabled children need help with self-care for example, eating, washing, dressing and toileting.

For many of these children, their needs are long-term and the majority live with their families who carry the day-to-day responsibility of caring for their child. In addition to focusing on improving the health interventions and support given to these children, there is a need to address the many other barriers that often result in their being excluded from family, school or community activities.

It is possible to look after very complex healthcare needs in this way at home, for example, children requiring long-term ventilatory support as Jo's story demonstrates. Guidelines are available on the principles underpinning the organisation and delivery of care locally.

Spending less time in hospital and feeling less tired were some of the positive benefits of home ventilation reported by children and families. Research shows that higher quality, more flexible and better coordinated nurse-led home care can improve the quality of life and health of children who use ventilators.

For increasing numbers of children there is a need for transition from children and young people's services to adult care. We are not doing this well at present and this area needs focused attention too.

Fulfilling potential

The overall aim is to provide high quality services for children and young people without compromising timely, skilled assessment, diagnosis and treatment by staff who have all the right competencies.

Our policies for service reform recognise that children are different, that they need to be looked after by people who understand their particular needs and that they should have services designed specifically for them and their families and to be treated in a suitable environment.

However, there can never be a top down approach to achieve these outcomes. Based on 2004 estimates, there are 11.7 million children under 18 years old in England. The distribution of this population is geographically uneven, ranging from 583,000 in the North East to 1.7 million in London. This means the solutions to the challenges we face will look different in different parts of the country. Reducing inequalities and ensuring we meet the needs of groups at risk of exclusion, such as children in care or from ethnic minorities, remains essential.

Innovative ways to provide services using assessment units, multi-disciplinary teams, outreach and IT should be considered with the aim of providing clinically and cost-effective services that emphasise safety, quality and sustainability.

The changes are also being driven by our commitment to provide age-appropriate services with an emphasis on prevention, earlier diagnosis of problems, better treatment, better co-ordination between services within health and with education and social care and better transition to adult services for those who need it. Children who need to attend hospital must be treated in facilities designed for them, with attention to the needs of adolescents as well. These requirements apply to children with emotional and mental health problems as much as those with physical diseases.

We now place a greater emphasis on what children, young people and their parents want. As a result, more care is being brought closer to home. People should have more of a choice based on good information and, in many areas, outcomes must continue to be improved.

For babies, children and young people, Primary Care Trusts, Children's Trusts and GPs need to pay greater attention to commissioning better services in the light of children's changing needs. This includes prevention as well as treatment, highly specialised care and care at home or in the local community, taking the opportunity of new locations.

The NHS has always changed and will go on changing as medicine and children's needs change. Reorganisation is about the service you get, not the buildings or the beds you think you might lose.

By ensuring we meet children's needs now, we give them the greatest opportunity to fulfil their potential in the future. In order to give children the best start in life, we need to address the social and emotional needs of very young children and their parents, as well as their medical and physical needs including providing health, parenting and educational support in children's centres and extended schools.

As a specialist in children's health, I passionately believe that we need to get it right for children and young people. Today's services are not good enough. That is why as National Clinical Director I believe the changes we are proposing must be about delivering the best care for the future.



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