

Foreword by Professor Sir Al Aynsley-Green Kt

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'Children are the living messages to a time we will not see.'
Neil Postman, *The Disappearance of Childhood*

This book is about children and their health today. The image above reminds us of the species we are talking about. She is a beautiful newly born infant girl, a citizen in her own right, showing her hard-wired ability to manipulate her caring adults by her rapturous gaze at the adult face. This eye-to-eye contact is a fundamental trigger in attachment – the process whereby the brains of adults, especially mothers, experience a surge of love hormones including prolactin and oxytocin that trigger our nurturing instincts. The gaze also stimulates the infant's own brain in its journey of emotional competence. Our love and commitment for our babies and children in our families triggered by these precious early moments of adult-child dialogue has ensured the survival of the human species.

Like all other newly born babies, she is defenceless, exquisitely vulnerable, and depends critically for her survival and for her long term potential on the care given to her by adults. The nurture of babies and children is not just the responsibility of parents and families, as vital as that is, but it should be everybody's business – communities, faiths, schools and professional staff as well as politicians.

Understanding, support and effective advocacy for the needs of children by politicians is especially relevant to the content of this book, since governments determine political priorities, define policy through legislation and allocate funding from taxation.

It could be argued that nations should be judged on their enlightenment not only by the commitment they give to children in policies but through the reality of their health, education and social outcomes as they progress into adulthood. These outcomes are a direct reflection of the quality of services and the nurture in society they have received.

Children are our nation's most precious resource. Political theorists from Karl Marx, through Winston Churchill and Tony Blair and Gordon Brown, have recognised this fundamental truth. I first visited Eastern Europe in 1979 and saw the high priority given to children, as the workers of the future, in those communist societies. Similar priority has been given to children's health in Cuba. Sadly, and without supporting a totalitarian approach to society, I have witnessed the progressive diminution of that priority as former Eastern European communist countries have moved to capitalist economies. Winston Churchill also reminded us that: 'There is no finer investment for any community than putting milk into babies' ('Four Year Plan for England' broadcast on 21 March 1943). More recently European Union theoreticians have argued the cause of investing in children to create the 'child-centred social investment strategy', and this became manifest in England through the *Every Child Matters* policy of the New Labour government.

Political rhetoric is important in setting a context and flying a signal, but it is ephemeral, subject to change in party political focus, and driven by external circumstance. What should matter most is sustained cross-party political will to recognise the importance of children and translate fine words into practical policy that supports the lives of children and their families.

So, how well are we doing for children and young people in the UK? Are the services fit for the purpose of supporting their needs?

Children, generally, are healthy and few die compared to 50 years ago. The culture of services has been transformed, for example, by accepting that parents should have unlimited access to their sick children in hospital, and be involved in making decisions in their care.

The increasing importance of the voice of children and young people is being realised based on Article 12 of the United Nations Convention on the Rights of the Child that states: 'Children have the right to say what they think should happen when adults are making decisions that affect them, and to have their opinions taken into account'.

No one today would inflict a procedure or a treatment without fully involving the child, depending on its level of understanding. But even young children receive patient-controlled analgesia after surgery, in which within very tight limits, they can adjust the rate of morphine infusion to meet their needs for pain relief.

Resources and facilities have improved such as attractive new children's hospitals that include wards purpose-designed for adolescents.

Major scientific advances in molecular medicine and genetics have transformed the understanding of the pathogenesis of diseases, their diagnosis and treatment, and immunisation has diminished the toll of polio, pertussis, rubella and meningococcal meningitis.

Take two-day old baby Peter (not his real name), for example, suffering from severe congenital neonatal hypoglycaemia due to excessive release of insulin. Until recently, this baby would have spent weeks in hospital with the ever-present risk of severe neurological damage caused by persistent hypoglycaemia during months of volatile medical treatment, eventually requiring total pancreatectomy to control the relentless hypoglycaemia. Now, advances in molecular genetics linked to new methods of imaging of the pancreas allow laparoscopic resection of a focal area of excess insulin release in the pancreas. Peter can expect to go home cured of the disorder without brain damage within a few days of diagnosis. There are countless other stunning examples of progress in every sub-specialty in paediatric medicine.

Despite these important and welcome developments, the result of the hard work of dedicated scientists and medical staff, the content of this book exposes the inconvenient paradox that all is not well for children and their health in the UK, with so many outcomes for our children falling way below the benchmarks of other developed nations. Why is this the case?

In 2000, Sir Ian Kennedy published his critical Inquiry into the scandal of children's cardiac surgery in Bristol, which amongst other conclusions found that 'more children died than might have been expected in a typical PCS [paediatric cardiac surgery] unit'. He exposed that nationwide, care for children was subordinated to the demands of adults; lack of understanding of what is different about children's services in people who matter; the view that children are healthy and services are satisfactory, and the ability to admit a sick child being a major success.

But he also exposed that children were not mainstreamed in government policy – they were an ‘add-on’, with key adult-centric priorities in the NHS that were not relevant. Children and young people being unable to vote have little political traction, and this coupled with a failure of leadership and of political advocacy by professional organisations led to their needs being under-recognised.

Ten years later, Kennedy re-visited children’s health services and showed that whilst there were patches of excellence, cultural barriers in government, and in services, perpetuated the isolation of policy, lack of responsibility for policy, no identified funding, poor use of data, the NHS not working with others, and a lack of financial investment.

The Kennedy Inquiry triggered the then Government to launch ‘a new crusade to improve the nation’s children’s health’, including a new role to be responsible for defining standards of care in a National Service Framework with the promise of ring-fenced money, imperatives, and hard targets to meet. The rhetoric created a massive expectation in the children’s health sector that at last there would be a transformation in the low standing of those services.

After four years of work, expense and involving over 300 experts – coupled with rigorous evidence as to what works and extensive consultation not least with children and young people themselves – the National Service Framework was ready for publication. It received international acclaim as an outstanding process for defining standards for children’s health care.

But then, unexpectedly, children were betrayed by politicians with the defined ‘must do’s’ turning to nothing more than ‘aspiration’ over a ten year period. The lack of political will to provide imperatives and resources created fury in the sector with a shadow of distrust lasting until now. A unique opportunity at a time of financial abundance to give children the priority they deserve was lost evermore.

Why did this happen? The inconvenient truths are:

- the ‘churn’ of ministerial appointments (six Ministers and three Secretaries of State in five years)
- failure to get continued focus for children’s health from the Government through successive Secretaries of State in the Department of Health
- overtaken by political fashion – ‘shifting the balance of power’ becoming the mantra in the Department of Health
- political indifference for children
- failure of Parliament to hold the Department of Health to account
- lack of media pressure
- silent voice of the sector and lack of concerted, effective and sustained advocacy.

In 2007, the New Labour Government launched *The Children's Plan* incorporating five outcomes – 'be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well being'.

As with the National Service Framework, this policy received international acclaim for the comprehensive way in which children and their services were regarded, with all Departments of State being held to account for their work that related to children and young people.

In 2010, within minutes of the new Coalition Government being announced, every image of the *Every Child Matters* policy was removed in what had been the Department for Children, Schools and Families, now re-named the Department for Education, the former Plan being systematically dismantled.

The Department of Health published in 2010 its policy statement, *Achieving Equity and Excellence*, timed to coincide with and, arguably, to neutralise Sir Ian Kennedy's highly critical report on the lack of progress in improving children's services. It has now published its report of the Children and Young People's Outcomes Forum, the product, as for the National Service Framework, of hard work by outstanding contributors. It defines principles with the potential to change the focus of children's health care to accountability through defined outcomes: putting children, young people and families at the heart of what happens; acting early and intervening at the right time; integration and partnership; safe and sustainable services; workforce, education, and training; knowledge and evidence; leadership, accountability and incentives.

The sceptic experiences déjà vu, seeing philosophies and words identical to those of the National Service Framework, and believes that without any political commitment to the outcomes, let alone the funding streams for implementation, the publication is destined to gather dust on the library shelves alongside the many other unimplemented policy declarations in recent years.

On the 19 February 2013, the Government announced a national pledge to reduce the number of excess deaths in children (some 1,600 per annum when compared to other developed countries), and starting a data revolution so the NHS and local authorities get better information they can use to improve the health of young people. The announcement also includes making sure children and young people are at the heart of the new health and care system, and that their voices are heard; and new roles and bodies have been created, including input by the Chief Medical Officer to make sure the issue stays top of the agenda by bringing health leaders together to improve children's health.

These comments and pronouncements are welcome, but the history of children's health policy is such that there is limited confidence that anything meaningful or substantial will change especially against the backdrop of national financial austerity.

The chapters of this book provide a compendium of hard evidence on the circumstance of children's health in the UK today. What the incontrovertible overall data cannot do, however, is to expose the real human cost of this circumstance on the day-to-day lives of individual children and their families. The voices of children and families are not evident. Who is listening to them?

Take, for example, Rachel and Simon (not their real names), the parents of five-year old Emily (not her real name), a child with complex congenital malformations and learning difficulties. 'Wading through treacle', they say. 'Who is in overall charge of my child? Why do I need 10 different appointments at different times to see the specialists involved in her care? What is going to happen to her as she grows up and becomes an adult? Who is responsible for integrating her education, health and social care needs? Why do we have to fight every inch of the way for her entitlements? Who cares?'

Or take Becky (not her real name), a 16 year-old with severe anorexia nervosa requiring admission to a specialist in-patient unit 150 miles away from her home because of the lack of specialist provision where she lives. Her parents express their frustration and exhaustion in having had to fight endlessly for their concerns to be taken seriously, coupled with the financial and social cost in travelling a round trip of some 300 miles to visit their sick daughter.

These are but two illustrations of the lived experiences that lie hidden behind the hard facts of the inadequacies of current services and the failure of political will that this book exposes. Who can deny the fear, the anguish, and despair, in seeing a much-loved child who has a disability or becomes sick? No one chooses to be the parent of such a child, and the children themselves certainly do not, yet where is there compassion in our society? Any one of us could be confronted with these realities in our families.

As Ingrid Wolfe, quoting Charles Dickens says in her chapter, 'It was the best of times, it was the worst of times'. The Victorian times were devastating for the lives of countless children.

Here is Elizabeth Barrett Browning in her poem, *The Cry of the Children*, published in 1843:

'Now tell the poor young children, O my Brothers
Look up to Him and pray;
So the blessed One who blesseth all the others,
Will bless them another day.
They answer, "Who is God that He should hear us
While the rushing of iron wheels is stirred?
When we sob aloud, the human creatures near us
Pass by, hearing not, or answer not a word.
And we hear not (for the wheels in their sounding)
Strangers speaking at the door;
Is it likely God, with angels singing round Him,
Hears our weeping any more?"'

But in the midst of so much despair, some people did listen and a social conscience began to stir. The social reformers – including Bramwell Booth, Joseph Rowntree, Josephine Butler, W.T. Stead, the Rev Waugh, Dr Barnardo and, above all, Charles Dickens – were leading public figures driven by outrage over how they saw the effects of society at that time on the lives and deaths of children. They founded famous organisations, many of which are still with us today, and courageous politicians including Lord Shaftesbury introduced education and employment legislation that transformed the lives of children.

Of course we cannot compare directly the appalling circumstance of children 150 years ago with today. But, are there not parallels? In 2013 we are currently experiencing the most challenging era for children, young people and their health for the last 30 years, driven by a disastrous financial environment leading to deep cuts to public services, coupled with political turmoil caused by ideological dogma as exemplified by the NHS re-organisation that continues apace.

Should there not be outrage that the lives of so many children and their families are blighted by the facts exposed in this book, despite current difficulties, still one of the richest countries of the world? Who speaks for them? Where is the evidence of concerted and effective political advocacy from the professional organisations that claim to have their best interests at their heart?

I issue a call to action by all who are concerned by the current plight of children and the threats to their services. The incontrovertible facts and a menu of recommendations are here in this outstanding book. So, to every reader, my challenge is if you really care about children, then what are you going to do about it?

As well as striving for national political focus and action through membership of our professional organisations, it is from the local level that change for children should be driven – the power of parents in exposing poor practice; the new responsibilities of staff in the light of the Inquiry into the scandal of care in Stafford to be ‘whistle-blowers’; effective leadership through the brigading of medical, nursing and all professional staff involved in the care of children – there is much to do and as Neil Postman said in his book *The Disappearance of Childhood*, ‘Children are the living messages to a time we will not see!’.

Their future lies in our hands now, and we cannot afford to continue to fail them.

A handwritten signature in black ink, appearing to read 'Al Aynsley-Green', written over a horizontal line.

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Sir Al started his career in medicine in London at Guy's Hospital, then developing his speciality of paediatric endocrinology through training and research in University hospitals in Oxford, England and Zurich, Switzerland.

He was Clinical then University Lecturer in Paediatrics and Fellow of Green College, University of Oxford, Professor of Child Health and Head of the School of Clinical Medical Sciences, University of Newcastle upon Tyne and then Nuffield Professor of Child Health and Executive Director for Clinical research and development at the Institute of Child Health and Great Ormond Street Hospital for Children, London.

He was appointed Chair of the first NHS Children's Taskforce and then the first National Clinical Director for Children in the Department of Health where he was responsible for defining the first national comprehensive standards of health care services for children, young people and expecting mothers. He was appointed the first independent Children's Commissioner for England in 2005, a post created by Parliament to be the independent voice for children and young people, implementing new ways of engaging with them, particularly those most invisible in society. Among his achievements was the exposing to

public and political view the injustices faced by children with mental ill health, those in conflict with the law, and those seeking asylum.

He stood down after his five years of tenure as Children's Commissioner in 2010 and is now Professor Emeritus of Child Health at University College London, and Founder and Director of Aynsley-Green Consulting, engaging with governments and organisations worldwide on children, childhood and children's services.