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Translating research into political advocacy to improve infant and child health

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ABSTRACT

Dramatic improvements have occurred in the overall health of our children driven by rigorous research translated into clinical practice. However, all is not well for too many, not only for their health but for other outcomes of their lives. These outcomes reflect poorly on how professional groups in child life and health have advocated effectively at the political level for the needs of children and for the services to support them.
Professional staff in child health, including those involved in neonatal care, must become more effective in translating research into political advocacy for the best interests of children. A scientific approach to political advocacy is needed that is equivalent in its rigour to the best of bio-medical research. Above all, the care of the newly born infant should not be seen in isolation, but in the overall context of childhood and the services to support children today.

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1. Introduction

Children, generally, are healthy and fewer die than 20 years ago. Scientific advances in molecular medicine and genetics have transformed knowledge of the pathogenesis of diseases, and have improved diagnosis and treatment so that conditions previously untreatable can now be cured. Prevention through immunisation has diminished the toll of polio, pertussis, rubella and meningococcal meningitis.

The culture of services has been transformed with parents having unlimited access to their children in hospital, and being involved in making decisions in their care. Resources have improved including purpose built children's hospitals and wards designed for the specific needs of neonates, children and for adolescents. Outstanding staff working with and for children are passionate, motivated and strive to promote their best interests.

Some of the most impressive and dramatic developments in child health have occurred in the care of newly born infants, these having been driven by the translation of high quality research into clinical practice, especially from understanding better the physiology and pathophysiology of the transition of the infant from being a foetus to a neonate.

Premature infants now survive at the limit of viability; improved understanding of respiratory physiology has led to better methods of ventilation support for the immature lung; the nutrition of the premature infant and better metabolic control have all contributed to the improved survival of critically ill infants. This survival is, however, not always without adverse consequence in terms of impaired neurological and physical development, and the economic cost of disability let alone the human costs to afflicted children and their families is substantial.

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Ethical and moral challenges are also at the heart of everyday practice in newborn intensive care wards.

Of special significance is the developmental model for chronic life-long disease. Barker's work on the foetal nutritional programming of adult disease has transformed our understanding of the antecedents of much adult mortality and morbidity [1]. The new science of epigenetics is adding to this knowledge.

Neonatology is, therefore, one of the most exciting and fast-moving specialities within medicine today. It lies at the cutting edge of high technology science; it sits at the interface between maternal health and foetal medicine with major implications for understanding and potentially preventing much adult disease; it has high public profile, attracts some of the best clinical scientists and is a powerful instrument for charitable resource generation.

Neonatal practitioners can be forgiven, therefore, for perhaps living in a culture disconnected from the realities and challenges of contemporary child life and health let alone the wider political environment. This review argues that the specialty needs to be embedded in an awareness of the broader context of child life and health and for this to inform its advocacy for the needs of newly born infants and their families. A key 'exam' question is to ask if all is well for the services and resources to support newly born infants to allow them to achieve their full potential in life. The starting point in answering this is to examine the context of childhood today.

2. The context of childhood today

There are unprecedented challenges facing children and childhood today in developed let alone developing nations. In the former, austerity, political ideology dominated by the needs of the elderly compounded by failure of effective leadership and advocacy from professional groups and their organisations have all led to poor outcomes in international league tables and national data sets for many aspects of the lives of children in a number of EU countries.

Whilst we should celebrate that countless children in England are loved in their families, are healthy, successful, work hard to achieve and are contributing to society, the circumstance of too many children is dire. Despite patches of excellence in services to support them, there is incontrovertible evidence of poor outcomes for many children in almost every aspect of their lives.

Some (by no means comprehensive) aspects of evidence from the UK to support this assertion include:

The landmark report by the Children's Society entitled '*A Good Childhood—Searching for values in a competitive age*' published in 2009, in which some 35,000 children participated, defined the key drivers preventing children and young people experiencing a good childhood [2]. These were excessive individualism in society, the soaring rate of family breakdown, relentless commercialisation of childhood, the competitive education environment and poverty. The Bailey Review into the commercialisation of childhood by the Mother's Union subsequently confirmed the unprecedented targeting of even very young children by the advertising agencies for profit [3].

In 2007, the UK ranked bottom of the UNICEF league table on the wellbeing of children in the richest countries of the world [4]. High poverty, poor health reflected in low birth weight and high infant mortality, poor family and peer relationships alongside risky behaviour including alcohol misuse, early sex and teen pregnancy were accompanied by low expectations and a high rate of young people Not in Employment, Education or Training (NEETs). Of special concern was the low self-assessed wellbeing of so many youngsters.

The position in the league table rose to 16th by 2013, [5] but whether this can be sustained in light of current turbulence is doubtful. Some important changes in health-related behaviour have occurred including a fall in overall alcohol consumption in young people (but associated with an increase in 'binge-drinking') and a decrease in teenage conceptions [6]. However, British girls have become the most obese in Europe.

The Chief Medical Officer for England in her report published in 2013 entitled '*Our Children Deserve Better*: *Prevention Pays*' comments that 'The United Kingdom should feel profoundly ashamed of its record on child health' [7]. This is despite Sir Ian Kennedy's report on the scandal of children's health services triggered by poor outcomes after cardiac surgery in Bristol over 10 years ago [8]. The CMO's report includes data on the unacceptable variation nationwide in outcomes for children's health.

The British Medical Association's report, also published in 2013, entitled '*Growing up in the UK*' defined the poor outcomes for many children and their health to the extent of being some of the worst in the developed world, concluding that 'Politicians have been failing children on a grand scale' [9]. The uncomfortable fact that some 1600 children die unnecessarily each year in the UK when compared to other EU countries is emphasized, this reinforcing the conclusions of the report by the Royal College of Paediatrics and Child Health '*Why children die*: *deaths in infants*, *children and young people in the UK*' [10].

The Council for Disabled Children has relentlessly documented the often overwhelming and appalling problems that families face in accessing their entitlements and services to support their disabled child's needs [11].

The current Children's Commissioner for England has defined children's concerns over the extent of alcohol misuse in their parents and families, [12] and there is a stark mismatch between the focus in Canada on the importance of foetal alcohol exposure being the most important preventable cause of disability alongside criminality and poor behavior and it's near invisibility in government's alcohol policy here.

Despite many children being protected effectively by hard working and motivated staff, the outcomes of many children in the care of the state are woefully below those in society generally, although recent policy to improve the rate of adoption is important. The failure of social care to protect children from sexual exploitation in Northern England and the ongoing record of children being killed by their families re-expose the major difficulties documented by Lord Laming in his enquiry into the murder of Victoria Climbie over ten years ago in protecting the most vulnerable children [13]. These challenges need to be set against the enormity of domestic violence in families with one episode being reported to the police every minute [14].

Over 70% of young people reoffend after imprisonment with high rates of suicide and self harm and the needs of the 200,000 children of prisoners have been ignored leading to especially poor outcomes of health, education and employment [15,16]. The first Children's Commissioner for England described the unmet needs of young mothers and their infants in prison in his report ten years ago [17]. There is little evidence that the circumstance of these groups of children has improved.

The overall education outcomes for British children as analysed in the recent PISA test data by the OECD are some of the worst in the developed world. Thus, the UK outcomes for literacy and numeracy are 23rd and 26th out of 65 countries in the international PISA ranking with many young people lacking the skills needed for modern employment [18]. Whilst welcoming the need for education reform, current policy with its relentless stressful focus on examination attainment in an ever-narrowing curriculum at the expense of creativity, sport and the arts is occurring at a time when more young people are seeking unmet help for emotional ill health and particularly when contemplating suicide. One in ten young people is believed to suffer a diagnosable mental health disorder, yet less than 25% are able to access the services they need [19]. The recent announcement on the creation of a 'Task Force' for child and adolescent mental health is welcome, this being but the latest in a series of government 'initiatives' during the last 10 years that have singularly failed to make the improvements that are needed in protecting the emotional health of our young.

The pernicious effects of rising inequality on every facet of life are well documented [20,21] and are likely to be made worse as a result