UNCRC 2015 Civil Society Submission

Written evidence submitted by the Royal College of Paediatrics and Child Health

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Introduction

The RCPCH welcomes the opportunity to provide input to the non-governmental organisation report to the United Nations Committee on the Rights of the Child.

If we compare ourselves with Sweden, the country with the lowest mortality for children and young people, (after controlling for population size among other variables), we find that in the UK every day five children under the age of 14 die who would not die in Sweden. This equates to the alarming figure of 132,874 person years of life being lost each year in the UK, the majority of which would be as healthy adults contributing to the country's social and economic strength.

But child mortality is just the tip of the iceberg. There are major unexplained and unacceptable variations in a number of key child health measurements. The latest *Atlas of Variation in Healthcare for Children and Young People*, shows the continuing wide and unwarranted disparities around the country in service provision, care and outcomes such as breastfeeding, low birth weight and looked after children.

Important indicators demonstrate real inequity in health, particularly in infant mortality, obesity and childhood accidents as well as amongst particular groups such as looked after children, those from black and minority ethnic groups and those with disabilities. Patients' expectations continue to increase at the same time as public spending is under substantial pressure.

At the same time, the main focus of health and social care policy from successive Governments has been on meeting the needs of an ageing population. From free TV licenses, bus passes and winter fuel allowances to the most recent guaranteed pension increase; these big ticket policies have made a welcome difference to many people towards the end of their lives. But equal focus must also be given to our younger generation, so that Britain is not only the best place to end life, but also begin life.

To fully deliver article 24 in the Convention on the Rights of the Child, we need to prevent children and young people from becoming unwell and we need to intervene early to enable our children to grow up into resilient teenagers and adults. This will reap significant benefits not only for our population but will also reduce pressures on the NHS in the long term as these young adults progress through their lives. Delivery of care must continue to shift out of hospitals and be shaped around service users. There also needs to be better integration and multidisciplinary models for delivering health services to children and young people in the community.

Mortality rates

In 2013, 2,686 babies died before their first birthday in England and Wales[1]. The infant mortality rate for babies of mothers born outside the UK was 4.2 deaths per 1,000 live births compared with 3.6 deaths per 1,000 live births for mothers born inside the UK. The highest

[1] Office for National Statistics (2015) *Childhood, Infant and Perinatal Mortality in England and Wales, 2013* ONS: London/ http://www.ons.gov.uk/ons/dcp171778_397789.pdf

infant mortality rates were for babies of mothers born in the Caribbean and mothers born in Central Africa. Babies of mothers born in the Caribbean also had the highest stillbirth rate[2]. In 2010, if the UK had the same all-cause mortality rate for children under 14 years as Sweden we could have nearly 2,000 fewer deaths among children in that age group per year. This equates to five fewer children's deaths per day.

One of the strongest themes emerging from the report *Why Children Die*[3] is the impact of poverty and social inequality on child mortality and children's life chances, illustrated by the fact that mortality rates are noticeably higher for babies born into low income households compared to those born into wealthier households. One in four children are living in poverty in the UK – in total 3.5 million children – and the number is set to rise in the future. By the next election it is estimated that more than four million children will be living in poverty. Poverty and inequality matters to child health and to the number of child deaths each year.

The government's next Child Poverty Strategy should focus in more detail on health inequalities and should be supported and sponsored by the Department of Health as well as the Department for Education, Department for Work and Pensions and Treasury. It should also be informed by and directly link to the work of Public Health England.

The Child Poverty Strategy should also set out a detailed step by step plan for how central and local government will meet the nation target to eradicate child poverty by 2020.

Epilepsy

A national audit of the quality of care for children with epilepsy, published in 2012, showed that 35% of children with epilepsy did not have an appropriate first assessment, and 40% did not see a paediatric neurologist when it was indicated and that less than half of children had specialist nurse care as recommended[4]. **NHS England should ensure that clinical teams looking after children and young people with known medical conditions make maximum use of tools to support improved communications and clarity around ongoing management such as introducing epilepsy passports.**

Asthma

A systematic assessment of variations in healthcare processes within the UK revealed substantial variations in some measures of care. For example, the emergency hospital admission rate for children with asthma ranges from 25.9 to 641.9 per 100,000 – a 25-fold difference[5]. **Further work is needed to assess how much of this variation is appropriate for differences in population need and how much is unwarranted.**

Diabetes

The NICE Clinical Guideline (CG15), states that all children and young people with diabetes over 12 years of age should receive seven key care processes in order to achieve optimum control over their disease and reduce the potential for serious health complications. The seven care processes include:

1. HbA1c (all ages to receive this process)
2. Height and weight
3. Blood pressure

[2] *Ibid*
[3] Wolfe et al (2014) *Why children die: death in infants, children and young people in the UK* RCPCH: London
[4] HQIP/RCPCH (2014) *Epilepsy 12: National report of Round 2 of the United Kingdom collaborative clinical audit of healthcare for children and young people with suspected epileptic seizures* RCPCH: London
[5] Department of Health (2013) *Annual report of the Chief Medical Officer 2012, Our Children Deserve Better: Prevention Pays* (Annex 9: Atlas of Variation in Healthcare for Children and Young People) HM Stationery Office: London

4. Urinary albumin
5. Cholesterol
6. Eye screening
7. Foot examination

With just over 16% of children and young people with diabetes in England and Wales receiving all seven of these key diabetes care processes, improvements in care are urgent to avoid preventable diabetic emergencies[6]. **Completing and recording these care processes can highlight problems at an early stage and allow action to be taken to reduce the significant risk of complications and lowered life expectancy associated with this life-long chronic disease.**

Transition

Transition from paediatric to adult care of young adults with chronic diseases and long term disabilities is poorly coordinated, often delayed, and usually managed through a single referral letter. In 2014, the Care Quality Commission[7] published its first thematic review of NHS services in England. The review looked at children's transition to adult services and found that some children's services stopping the care they provide before the equivalent adult services have started, families felt confused and distressed by the lack of information and support given to them and good practice guidance had not been followed. The review also found that only 50% of of young people and their parents said they had received support from a lead professional during the process leading up to transition to adult services. **There is a range of best practice in transition that has been developed by providers. This needs to be widely shared across the health system to ensure that young people and their parents experience timely and effective transition.**

Personal, social and health education (PSHE)/SRE

Ofsted reported in May 2013 that learning in PSHE required improvement or was inadequate in 40% of schools surveyed and that sex and relationships education required improvement in over a third of schools[8]. This compares poorly to Ofsted survey reports in some other subjects. The trend in the quality of PSHE is also cause for concern. Ofsted found in 2010 that PSHE was good or outstanding in three-quarters of schools surveyed and so the situation appears to have worsened over time. **The Department for Education should ensure that high quality, comprehensive PSHE programmes are implemented across all primary and secondary schools.**

Child and Adolescent Mental Health Services (CAMHS)

It is known that 50% of mental illness in adult life (excluding dementia) starts before age 15 and 75% by age 18[9]. Increasing caseloads and limited resources have led to a reduced number of specialist services. With this in mind it is concerning to hear that the only new referrals that CAMHS is accepting are young people who present with active life threatening conditions. Conditions commonly cited as excluded from a CAMHS service were Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), emotional problems, anxiety, children aged under 5, behavioural problems, post-abuse and trauma intervention and learning disability. **Efforts need to be made to support the delivery of effective CAMHS by addressing workforce and training issues and shortfalls in resources as there is an increasing gap between physical and mental health services.**

[6] HQIP/RCPCH/NPDA (2015) *National Paediatric Diabetes Audit Report 2013-14* RCPCH: London
[7] Care Quality Commission (2014) *From the pond into the sea: children's transition to adult health services* CQC: London
[8] Office for Standards in Education, Children's Services and Skills (2013) *Not yet good enough: personal, social, health and economic education* Ofsted: London
[9] Dunedin Multidisciplinary Health and Development Research Unit. Welcome to the Dunedin Multidisciplinary Health and Development Research Unit (DMHDRU). http://dunedinstudy.otago.ac.nz/

There are also frequent anecdotal reports of services having long waiting lists and of thresholds being too high in terms of referrals of children and young people with less severe problems not being accepted. The multi-agency nature of services allow the potential for a lack of co-ordination or integration between agencies which, particularly at a time of shrinking budgets, may mean that children and young people fall through the net. **The Department of Health should set out an action plan for improving CAMHS encompassing all levels of provision with a clear focus on prevention and early intervention, backed by additional resources, to ensure there is parity of esteem for children and young people, particularly for those most at risk of mental health difficulties (eg. looked after children, children involved in youth justice and children who have been excluded from school, children with disabilities, children who have experienced abuse and neglect).**

Looked after children

For local authorities in England, the percentage of looked after children (in care for at least 12 months) who had their annual health assessment ranges from 50% to 100%[10]. The percentage of looked after children who had their teeth checked by a dentist ranges from 9% to 100%[11]. **To tackle the variation in access to the minimum standard of healthcare for looked after children requires coordinated effort from a range of local professionals. They must ensure that routine health assessments are carried out, services are commissioned to adequately deliver assessments and other healthcare needs and that access to healthcare is regularly assessed and reported, with the appropriate services being held accountable for failures in access or provision.**

Low birth weight and smoking in pregnancy

Smoking in pregnancy is a risk factor for preterm birth and being born small for gestational age[12]. Large variations are seen across the country in the proportion of women who smoke at the time of delivery (2.9% to 29.7%) and live and stillborn infants who have a birth weight less than 2500 g (4.7% to 11%). The percentage of women who currently smoke at the time of delivery ranges from. Socio-economic deprivation is known to be associated with both maternal smoking rates and incidence of low birth weight. Many factors can influence outcomes related to antenatal health, however, variation in the quality and access to antenatal and perinatal healthcare may account for unwarranted variations in perinatal mortality. **The Department of Health, NHS England, Public Health England, Health Education England and the Royal Colleges should progress implementation of the recommendations outlined in 'Smoking cessation in pregnancy: a call to action' with particular focus of carbon monoxide screening in to routine pregnancy care.**

From 2015 Public Health England and local authorities should set out and monitor new national and local targets for reducing smoking rates across all stages of pregnancy and early parenthood.

Breastfeeding

In local authorities in England, the percentage of infants who are totally or partially breastfeeding by the 6-8 week infant examination ranges from 19.7% to 82.8%[13]. The proportion of children being breastfed is heavily influenced by socio-economic factors, with deprivation being associated with lower levels of breastfeeding. New mothers vary in the degree of support they need to initiate and sustain breastfeeding. Variation in the provision of local community midwifery, health visitor and perinatal care will significantly impact on rates of breastfeeding among local authorities. **Commissioners should establish whether**

[10] Department of Health (2013) *Annual report of the Chief Medical Officer 2012, Our Children Deserve Better: Prevention Pays* (Annex 9: Atlas of Variation in Healthcare for Children and Young People) HM Stationery Office: London
[11] *Ibid*
[12] *Ibid*
[13] *Ibid*

there is adequate support for mothers and families, not only to establish breastfeeding but also to prolong its duration. This should include improving education and dissemination of public health messages and aimed at groups where rates are found to be especially low.

About the RCPCH
The College is a UK organisation, which comprises over 15,000 members who live in the UK, Ireland and abroad and plays a major role in postgraduate medical education and professional standards.

The College's responsibilities include:

- setting syllabuses for postgraduate training in paediatrics
- overseeing postgraduate training in paediatrics
- running postgraduate examinations in paediatrics
- organising courses and conferences on paediatrics
- issuing guidance on paediatrics
- conducting research in paediatrics
- developing policy messages and recommendations to promote better child health outcomes.
- developing service delivery models to ensure better treatment and care for children and young people.

For further information please contact:

Emily Arkell, Head of Policy
Royal College of Paediatrics and Child Health, London, WC1X 8SH
Tel: 020 7092 6096 | Email emily.arkell@rcpch.ac.uk