Why children die: death in infants, children and young people in the UK Part C

July 2014

A POLICY RESPONSE FOR WALES TO THE REPORT 'WHY CHILDREN DIE: DEATH IN INFANTS, CHILDREN AND YOUNG PEOPLE IN THE UK – PART A'

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Why children die: death in infants, children, and young people in the UK
Part C

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Foreword

Children in the most deprived areas of Wales are almost twice as likely to die in a given year as those from the least deprived areas[1]. It is simply unacceptable that a child's chances of survival are so heavily influenced by the social and economic circumstances into which they are born. *Why children die: death in infants, children and young people in the UK – Part A* shows how reducing poverty and inequality are crucial steps towards reducing preventable child deaths.

In June 2014, a report by the Commonwealth Fund declared the NHS the world's best healthcare system[2]. The only serious black mark against the NHS is its poor record on keeping people alive – on this measure the UK came tenth out of 11 countries. But, say the authors, the healthcare system cannot be solely blamed for this issue; social and economic factors are clearly at play.

Children and families need to be empowered with the knowledge, skills and resources for the best start in life. We need better support for parents to adopt healthy behaviours during pregnancy and early infancy, we must design the places where children live, learn and grow to maximise their health and safety, and as young people progress through adolescence, we have a duty to ensure they are resilient and prepared to make positive life choices.

As healthcare professionals, we cannot shy away from our responsibility. The UK has similar prevalence, but poorer outcomes than similar countries when it comes to control of childhood conditions such as type 1 diabetes, epilepsy and asthma. We should be taking steps such as making sure every child with a condition - for example asthma and epilepsy - has a dedicated plan, and ensuring all healthcare professionals are confident and competent in recognising a sick child.

We must also recognise existing progress in Wales. The *Rights of Children and Young Persons Measure 2011* committed Welsh Ministers to give due regard to the articles of the UN Convention on the Rights of the Child, which includes a commitment to reduce child mortality. Additionally, the work of the Public Health Wales Child Death Review Programme provides a strong foundation of evidence from which policies can be developed to reduce child mortality in Wales. Furthermore, existing initiatives such as the *Tobacco control action plan for Wales*[3], the *Active Travel (Wales) Act 2013*[4] and the *Together for Mental Health Strategy 2012-2016*[5] represent a clear framework within which we can make improvements.

We must, however, continue to set high aspirations. Those of us who work to improve, and are advocates for, the health of infants, children and young people have a duty to better understand the reasons why children die and do all we can to reduce the number of these avoidable deaths. We have some of the best doctors and best medical equipment in the world, but we still have a long way to go to ensure our society delivers the very best for our children and young people.

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Introduction

In 2011 there were 222 registered child deaths in Wales. Between 2002 and 2011, 61% of deaths were in children under one year of age, 20% in children aged between 12 and 17 years, and 19% in children aged one to 11 years[1]. Although child death rates are largely similar between England and Wales, the mortality rate in children aged between 15 to 19 years is higher, at 33 per 100,000 in Wales compared with 27 per 100,000 in England[1].

Although *Why children die: death in infants, children and young people in the UK – Part A (Why children die)* argues for specific measures to be taken by the UK Government to tackle poverty and inequality, there is much that the Welsh Government, Public Health Wales, NHS Wales, local health boards and local government can do to reduce the impact of poverty and inequality on children's health outcomes to ultimately reduce the number of child deaths in Wales. The recommendations set out in this paper therefore take a comprehensive approach to tackling the causal risk factors for premature death during childhood, looking specifically at where, as a result of devolved powers, the Welsh Government and other key stakeholders can maximise opportunities for children in Wales to survive and thrive.

The recommendations cut across two key areas of action to reduce mortality as outlined in *Why children die*: health systems and organisations; and healthcare and public health. This policy response builds on the findings of *Why children die,* but also looks at the extensive evidence base which has been developed by the Public Health Wales Child Death Review Programme.

Health systems and organisations

Tailoring the health system to the needs of infants, children and young people

Why children die highlights how the way we deliver healthcare, funding systems, and the emphasis on primary care can all affect the lives and health of infants, children and young people. Flexibility in the way we deliver healthcare to children and families in Wales is vital for enabling services to adapt to children and young people's evolving needs and to optimise health their and safety.

Recommendation 1

The Welsh Government and NHS Wales should develop and pilot innovative and flexible multi-disciplinary models for delivering health services to children and young people in the community, with a focus on partnership working across the health, social care and education sectors and with attention given to improving the interfaces children encounter as they progress through primary, secondary and tertiary services and as they transition to adult care.

Healthcare and public health

Maximising health and wellbeing during pregnancy and infancy

Over half of childhood deaths occur during the first year of a child's life. Deaths during infancy are strongly influenced by preterm delivery and low birthweight: risk factors which disproportionately and alarmingly affect those most disadvantaged in our society[6]. In 2011, 7.1% of live births in Wales were born preterm (<37 weeks gestation) and 5.4% of babies were born at a low weight[7].

Despite smoking being an important modifiable risk factor for premature death during infancy, in 2010 smoking levels before or during pregnancy were highest in Wales compared with the other UK nations[8]. The continued implementation of Actions 3.8[i] and 3.9[ii] of the *Tobacco control action plan for Wales*[3], however, signals a positive step towards reducing these numbers.

Young maternal age is another risk factor for death throughout early childhood[9]. Teenage pregnancy in Wales is correlated with increased deprivation[7], signalling a need for improved access to high-quality sexual and reproductive health services, particularly in deprived areas, in addition to comprehensive Sex and Relationships Education which is underpinned by a sound evidence base.

Supporting parents, particularly young parents and those in deprived areas, is vitally important for reducing risk of premature death. Ensuring access to universal health visiting services in addition to more intensive interventions through Flying Start[iii] and further targeted support, such as the Family Nurse Partnership[iv], can play an important role in reducing the impact of poverty and inequality on child health outcomes.

Health during infancy can also be maximised through breastfeeding, therefore a continued effort to increase breastfeeding rates is needed. For infants born preterm in particular, breast milk has been shown to be of considerable additional benefit, associated with a reduction in potentially life-threatening conditions such as infection and inflammation of the bowel tissue known as necrotising enterocolitis[10].

Sudden Infant Death Syndrome (SIDS) also warrants particular consideration. In Wales, 13% of deaths during infancy have been found to be due to SIDS or some other unknown cause of death[1]. The Child Death Review Programme is currently undertaking a review of sudden unexpected deaths, associated with sleep, of children under two years of age which should provide further insight on ways to keep children safe, and the findings of which should be reflected in future policy and initiatives.

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[i] Action 3.8 - *Public Health Wales will work with Local Health Boards to further strengthen referral pathways between maternity units and Stop Smoking Wales to increase pregnant smokers' access to smoking cessation and to ensure that recommendations contained in NICE guidance on Quitting Smoking in Pregnancy and Following Childbirth (NICE 2010) are implemented*

[ii] Action 3.9 - *Public Health Wales will also work with Local Health Boards and NHW Wales Informatics Service (NWIS) to improve data collection on smoking rates in pregnancy as part of routine maternal and child health record systems*

[iii] Flying Start is the Welsh Government targeted Early Years programme for families with children under four years of age in some of the most deprived areas of Wales – http://wales.gov.uk/topics/childrenyoungpeople/parenting/help/flyingstart/?lang=en

[iv] The Family Nurse Partnership (FNP), adapted from the US, offers first time parents under 20 years of age intensive, structured, home visiting by specialist nurses who have been trained appropriately. The programme is currently being piloted and evaluated in England through a large-scale randomised controlled trial due to report initially in 2014 - http://www.fnp.nhs.uk/

Recommendation 2

Public Health Wales should continue to work with Local Health Boards in implementing Actions 3.8 and 3.9 (smoking in pregnancy) of the *Tobacco control action plan for Wales*[3], and from 2015 set and monitor new national and local targets for reducing smoking rates across all stages of pregnancy and early parenthood.

Recommendation 3

The Welsh Government should ensure that all schools make provision for high-quality, evidence based, sex and relationships education, and that through this and wider personal and social education (PSE) programmes, young people are taught the basics about the importance of healthy behaviours during pregnancy.

Recommendation 4

The Welsh Government should task Public Health Wales to carry out an annual audit of measures being taken in areas with high rates of teenage pregnancy to reduce these rates. This data should be mapped against the sufficiency of local sexual and reproductive health services and education programmes, with the Welsh Government holding Local Health Boards to account for progress.

Recommendation 5

NHS Wales should ensure that all maternity services obtain UNICEF UK Baby Friendly Initiative accreditation by 2016.

Recommendation 6

Public Health Wales should work with the Welsh Government, NHS Wales and representatives of Local Health Boards to develop a national strategy for the promotion of breastfeeding. This should be wide ranging and evidence based with progress evaluated annually. In addition to continued support from health visiting and other key services, a strategy should consider actions such as:

- raising awareness of the benefits of breastfeeding
- ensuring infrastructure which supports all women to initiate and maintain breastfeeding
- ensuring neonatal services recruit staff or train existing staff to deliver specialist breastfeeding advice and support.

Recommendation 7

The Welsh Government should prioritise universal access to health visiting services across Wales in addition to a national roll-out of Flying Start to ensure all families have access to services that can respond appropriately to need. Consideration should be given to the introduction of the Family Nurse Partnership initiative to all first time mothers under 20 years of age in Wales.

Recommendation 8

Public Health Wales, in partnership with Local Health Boards, should develop a targeted awareness campaign to promote safe sleeping, raising awareness of the potential risks of co-sleeping and considering the additional needs of more vulnerable families where multiple risk factors may be present, e.g. parental smoking. Consideration should also be given to the findings, once available, of the Child Death Review Programme's review of sudden unexpected deaths of children less than two years of age associated with sleep.

Reducing deaths from injuries and poisoning

A large proportion of preventable deaths during childhood and adolescence in the UK occur in the context of children and young people's interactions with their external environments. This highlights a need to better equip children and families with the knowledge, resources and appropriate public spaces in order to facilitate safety in the home and in the community and reduce the incidence of unintentional injury.

The introduction of the *Active Travel (Wales) Act 2013*[4] is a welcome step for improving safe walking and cycling routes in communities, however in addition to this we must ensure young people are equipped with the knowledge, skills and experience for safe driving. *Why children die* highlights road traffic accidents as a major cause of preventable death, consistent with findings from the Child Death Review Programme, which has found that between 2002 and 2011, road traffic collisions accounted for 39% of all external cause deaths in children in Wales. Loss of control has been highlighted as a critical factor in many crashes, which is often related to a lack of driving experience[11].

Recommendation 9

Local authorities should make maximum use of Integrated Children's Centres, Flying Start and safety equipment schemes to educate and equip parents to keep their children safe; including but not limited to water safety, safe sleeping, pet safety and blind cord injury prevention.

Recommendation 10

The Welsh Government should use the opportunity of the introduction of the *Active Travel (Wales) Act 2013*[4] to provide further guidance to local authorities:

- to introduce 20mph speed limits in all built-up areas
- to ensure that all local transport and spatial plans are overseen by public health experts to confirm that they will promote the safety and wellbeing of children.

Recommendation 11

The Welsh Government should pursue mechanisms for the introduction of a Graduated Licensing Scheme for novice drivers.

Promoting mental health and reducing risk-taking behaviours

Why children die highlights adolescence as the second riskiest time for death under 19 years of age in the UK. This pattern is consistent in Wales, with 20% of child deaths occurring between the ages of 12 and 17 years, with intentional self-harm accounting for around four deaths per year[1]. Data on the prevalence of mental ill health in children and young people in Wales has not been published since 2004, following the British Child and Adolescent Mental Health Survey, highlighting a need for up-to-date research to better aid planning of mental health services.

The Child Death Review Programme *Thematic Review of deaths of children and young people through probable suicide* highlights the importance of interventions to promote social and emotional wellbeing in schools, preventing alcohol and other substance misuse, and ensuring 'gatekeepers', including school and healthcare staff, are equipped to recognise and intervene when there are early signs of distress[12]. The review also highlighted several other risk factors for suicide in young people, including previous abuse, bullying and self-harm.

The *Together for Mental Health Strategy 2012-2016*[5] outlines clear actions for central and local government agencies to ensure effective access for children and young people to Child and Adolescent Mental Health Services (CAMHS) and to improve their overall resilience. Implementation of these actions will be an important step towards improving mental health outcomes.

Recommendation 12

The Welsh Government should ensure that evidence based comprehensive personal and social education (PSE) programmes are implemented across all primary and secondary schools which foster social and emotional health and wellbeing, through building resilience, and specifically tackling issues around social inclusion, bullying, drug and alcohol use, and mental health.

Recommendation 13

Mirroring the recommendation of the Child Death Review Programme, the Welsh Government should pursue mechanisms to restrict the access of children and young people to alcohol. This includes a minimum price per unit, regulation of marketing and availability, and action on under-age sales.

Recommendation 14

Early identification of mental health difficulties should be established as a core capacity of all health, social care and education professionals who work with children and young people through the promotion and evaluation of educational resources such as the MindEd e-portal across the children's workforce.

Recommendation 15

The Welsh Government should commission a regular survey to identify the prevalence of mental health problems among children and young people in Wales to provide current data to aid planning of healthcare services. This may be combined with a UK-wide prevalence survey.

Recommendation 16

The Welsh Government should continue implementation of *Together for Mental Health Strategy*[5] ensuring that there is parity of esteem for children and young people experiencing mental health difficulties, and effective access to services, particularly for those most at risk of suicide, including looked-after children, children involved in youth justice, children who have been excluded from school, and children with a history of self-harm.

Reducing healthcare amenable deaths

The importance of high-quality healthcare for children in the community and in acute settings is also highlighted in *Why children die*. Children, young people and their families must be confident that health issues will be identified early, that they will receive the safest possible care, and that they are supported appropriately in the community to manage any ongoing conditions.

Health plans have been identified as important tools for managing medical conditions, with asthma and epilepsy being two examples of this. The National Review of Asthma Deaths (NRAD) has recommended that all people with asthma have a personal asthma action plan, and that parents and children, and those who care for or teach them, should be educated about managing asthma[13]. This reinforces previous recommendations from the Child Death Review Programme that schools in Wales should have a healthcare plan for children with severe asthma[1]. It also reflects the recommendation of the Child Health Reviews – UK review of epilepsy deaths in children which highlighted the importance of coordinated care for children with epilepsies through the introduction of epilepsy passports[14].

It is therefore vitally important that educational settings are well equipped to manage children and young people with medical conditions. The Welsh Government has published guidance, *Access to Education and Support for Children and Young People with Medical Needs*[15], which provides detail on the importance of individual healthcare plans. A recent amendment to the Children and Families Act 2014 now ensures schools in England have a duty to support students with medical conditions[16]. A review of how the existing Welsh guidance is adopted and consideration given to whether a similar legislative duty for Welsh schools would improve care received by children and young people in schools would be welcomed.

Recommendation 17

NHS Wales and relevant professional associations should ensure all frontline health professionals involved in the acute assessment of infants, children and young people utilise resources such as the *'Spotting the sick child'* web resource and complete relevant professional development so they are confident and competent to recognise a sick child.

Recommendation 18

NHS Wales should ensure that clinical teams looking after children and young people with known medical conditions make maximum use of tools to support improved communication and clarity around ongoing management, for example:

- through the introduction of epilepsy passports or asthma management plans where appropriate
- by supporting all schools to implement guidance outlined the Welsh Assembly Circular, *Access to Education and Support for Children and Young People with Medical Need*[13], in particular healthcare plans.

Recommendation 19

The Welsh Government should review the use and implementation of healthcare plans as set out in *Access to Education and Support for Children and Young People with Medical Needs*[15], and following this, consider the introduction of a legislative duty to support pupils with medical conditions in schools.

Recommendation 20

NHS Wales should ensure all adverse events in hospitals which may have contributed to the premature death of an infant, child or young person are reviewed and the findings widely disseminated to enable clear recommendations and guidance to be developed to enable service improvement. Information captured as part of *Putting things right*[v] may be used to inform this process.

[v] When concerns are raised about the care received through NHS Wales, *Putting things right* provides a framework to report issues http://www.puttingthingsright.wales.nhs.uk/

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