

# A Focus on Children and Non-Communicable Diseases (NCDs)

**The NCD Alliance**  
Putting non-communicable diseases  
on the global agenda

**REMEMBERING  
OUR FUTURE  
AT THE  
UN SUMMIT ON NCDs,  
SEPTEMBER 2011**

This position paper has been prepared by the Child-focused Working Group of the NCD Alliance, and is addressed to the representatives of UN Member States and all others participating in the UN Summit on Non-Communicable Diseases (NCDs), being held at UN Headquarters in New York in September 2011



Recommendations for UN Member States to guarantee that the  
'best interests of the child' is a primary consideration in policy formulation related to NCDs  
United Nations Convention on the Rights of the Child 1989, Article 3(1)



International  
Diabetes  
Federation



International Union Against  
Tuberculosis and Lung Disease  
Health solutions for the poor



WORLD HEART  
FEDERATION\*

# FIVE CHILD-SPECIFIC RECOMMENDATIONS ON NCDs

The Child-focused Working Group of the NCD Alliance proposes five key recommendations for action by UN member states and international agencies for the UN Summit on NCDs:

## i. Leadership

- Inclusion of all UN agencies and other multisectoral stakeholders in child-focused efforts to address the underlying social determinants of health relevant to NCDs
- Sustained and strong high-level public, private and political support for a framework of specific commitments that integrate child-specific, lifecourse considerations within NCD policies and actions
- Establishment of clear funding mechanisms to specifically support collaborative action to prevent, diagnose, treat and research NCDs in children
- Empower and enable children and young people to have a voice within decision-making processes that affect themselves
- Broadcast the message that the vast majority of children and youth who are diagnosed with an NCD can and should live full and productive lives, free from stigma and shame

## ii. Prevention

- Ensure national policies on agriculture, trade, industry, education, health and transport shape social determinants linked to NCDs so that they promote good health of families and children. Examples include, but are not limited to, those social determinants that promote maternal nutrition and health, healthy diets, breastfeeding and physical activity, and reduce harmful alcohol, tobacco and air pollution exposure (notably unsafe cook-stoves)
- Ensure integration of feasible and cost-effective methods of primary, secondary and tertiary prevention of NCDs into pediatric primary care settings and resources
- Prioritise establishment of cost-effective Newborn Screening programs in all countries
- Accelerate implementation of the WHO Framework Convention on Tobacco Control and child-focused efforts to prevent initiation of smoking and exposure to secondhand smoke

## iii. Diagnostics and treatment

- Strengthen health systems to provide child-centered care across different levels of the health system
- Deliver cost-effective and affordable essential drugs and technologies for all children
- Ensure investment in training and education of health professionals in specialties dealing with NCDs in children, and prioritise having a skilled birth attendant at every birth, to prevent maternal and child deaths, and reduce asphyxia and cerebral palsy
- Promote community-based action that supports children and families who are living with NCDs to ensure children enjoy the highest quality of life possible
- Ensure that national health insurance schemes include coverage for NCDs affecting children

## iv. International cooperation

- Raise the priority of children within global NCD agendas, and increase funding for child-specific actions
- Encourage South-South and North-South knowledge sharing to escalate efforts for strategic, systematic and sustainable change that will improve the lives of children now and in the future
- Ensure the appropriate allocation of resources by UN agencies with a primary mission that includes children, such as, but not limited to UNICEF, UNDEP, UNWomen, UNFPA and WHO

## v. Monitoring, reporting, research and accountability

- Urgent focus on child-specific health data and registers relating to NCDs
- Identify ambitious child-specific targets and transparent reporting systems to monitor progress on priority child-specific actions
- Establish key child focused forums for sharing updates and regular reports on progress on these national and international commitments to children

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## 1. INTRODUCTION

A **Non-Communicable Disease** (or NCD) is generally agreed to be a medical condition or disease which is non-infectious, of long duration and generally slow progression. Sometimes referred to as “chronic diseases”, NCDs are similar to HIV and TB in that effective preventive, screening and diagnostic measures often exist, and strong models for chronic care management are required for those who are already affected.

NCDs threaten human health, development and the achievement of the Millennium Development Goals. Worldwide, NCDs currently represent 63% of global deaths (36 million deaths), and 80% of these are in low and middle-income countries. Left unchecked, it is estimated that NCDs will be responsible for 73% of all deaths by 2020. Most of this increase will be accounted for by emerging NCD epidemics in developing countries.

On 19 and 20 September 2011, the United Nations will hold its second-ever health-related Summit on the prevention and control of non-communicable diseases (NCDs)<sup>1</sup>. There is cause for optimism: the first health-related UN Summit (held in 2001 for HIV/AIDS) was extremely effective, resulting in a coordinated global response to HIV/AIDS and creation of the Global Fund.

Member states have already determined that the UN Summit on NCDs will focus on the four most prominent NCDs, namely cardiovascular diseases, cancers, chronic respiratory diseases and diabetes, and the common risk factors of tobacco use, alcohol abuse, unhealthy diet and physical inactivity. This is a practical approach to a complex problem: the four diseases selected cause an estimated 36 million deaths each year with 80% of these deaths occurring in low and middle-income countries.

However, in late 2010 concerns were raised that children risked being systematically excluded from the NCD discourse. The terminology in common use at the time (such as “chronic disease” and “lifestyle disease”) maintained a focus on adults, neglecting the fact that children are not only affected by all four of the key NCDs, but moreover are the cornerstone to a lifecourse (whole of life) approach to primary prevention and risk factor management.

This document serves to promote the profile of children within the NCD discourse leading into the UN Summit on NCDs in 2011, and it is hoped that children will be included within discussions, policy development, and tangible outcomes. As with the importance of considering children within the HIV movement, this paper will seek to demonstrate that children are not only living with and at risk of NCDs, but must also be core to global efforts to prevent and control NCDs. Only in this way will we fulfil our collective responsibility to progressively realising the rights of all children (and paradoxically adults also) to health and life.

By stepping above our respective disease-specific environments and working together as a global community passionate about the importance of integrating children within the NCD discourse, we intend to show that sustainable change is possible, and it is imperative that we work together to protect and fulfill the rights of the world’s children with respect to NCDs.

**The Child Focused Working Group of the NCD Alliance calls on member states to uphold their international commitment to the rights of the child and guarantee that children are “a primary consideration” during all discussions and during the formulation of the Outcomes of the UN Summit on NCDs in September 2011. Children must not be left off the agenda.**

## 2. ACHIEVING SOCIAL JUSTICE: UPHOLDING THE RIGHTS OF THE CHILD

The international community has recognised that children are vulnerable and, as such, require and are entitled to a specific set of human rights guaranteeing special care, assistance and protection.<sup>2</sup> In September 1990, this was realised when the United Nations Convention on the Rights of the Child (“the Convention”) entered into force providing children with a wide range of civil, political, economic, social and cultural rights. To date there are 193 parties to the Convention. It is the United Nations most widely ratified international legal instrument with only two member states, the USA and Somalia, having not ratified the Convention. The almost universal ratification is a clear commitment by the international community to the importance of children within our society.

At the heart of the Convention on the Rights of the Child is the universally accepted principle that “In all actions concerning children ... best interests of the child shall be a primary consideration”.<sup>3</sup> Article 1 of the Convention on the Rights of the Child defines a child as “every human being below the age of eighteen years”; therefore, when referring to protections afforded to a “child” this includes youth and adolescents. The individual rights enshrined in the Convention provide a legitimate claim for children to social justice rights, including the right of the child to the highest attainable standard of health and facilities. Article 24 of the Convention declares that:

- (1) State parties recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. State parties shall strive to ensure that no child is deprived of his or her right of access to such health care services
- (2) States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:
  - a) To diminish infant and child mortality;
  - b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
  - c) To combat disease and malnutrition, including within the framework of primary health care ... ;
  - d) To ensure appropriate pre-natal and post-natal health care for mothers;
  - e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition ... ;
  - f) To develop preventive health care, guidance for parents and family planning education and services ...
- (4) State parties recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. State parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.<sup>4</sup>

In ratifying the Convention on the Rights of the Child, member states made a commitment to uphold this right to the highest attainable standard of health and facilities and to “undertake all appropriate legislative, administrative and other measures for the implementation of the rights”.<sup>5</sup> As such, the rights of the child provide an element of accountability to governments and other organisations to ensure that these rights are being progressively realised. The international community, in its almost universal ratification of the Convention on the Rights of the Child, has shown a clear commitment to upholding and protecting the rights of the child, however, when it comes to addressing NCDs, children are too frequently left off (or insufficiently acknowledged in) the policy agenda.

It is important to acknowledge that a lack of resources is not always the sole barrier to the attainment of social justice rights of children; a lack of understanding of the problems and possible solutions also impedes efforts for change. What follows is evidence that the fulfilment of child health rights related to NCDs is possible and results achievable.

Acknowledgement: CLAN (Caring and Living As Neighbours) Inc

### 3. CHILDREN REQUIRE SPECIAL ATTENTION AND MUST BE INCLUDED IN ALL NCD POLICIES

Children are especially vulnerable and powerless. They often have no voice to advocate for their own needs, and yet they face unique challenges and have special needs. The period of rapid growth and development that occurs in childhood has a profound impact on future health and quality of life enjoyed in adulthood, and represents a “golden window” of opportunity in terms of improving the overall lifetime health of populations and promoting rights to health for all. While the Moscow Declaration<sup>6</sup> on NCDs and the World Health Assembly<sup>7</sup> recognised that NCDs affect women and men differently, these documents failed to specifically refer to children, the impact NCDs have on children and the centrality of children to a lifecourse approach to NCD prevention.

It is imperative that children’s issues are an integral part of the global NCD discourse. Any strategy that adopts a lifecourse approach to NCD prevention will offer the greatest chance of overcoming key NCD risk factors and realising the rights of all to health and life. A predominant focus on adults will systematically neglect important opportunities to reduce NCD risk factors from the earliest possible stages. By contrast, a focus on children promotes generational and population-based change, and empowers a pro-active approach to the primary, secondary and tertiary prevention of NCDs.

Unfortunately, there is a common misconception that NCDs do not affect children, but are diseases of adulthood only. This is patently false. NCDs and their risk factors have an enormous impact on the health of children. Cancer, diabetes (both Type 1 and Type 2 diabetes), chronic respiratory diseases (such as asthma), obesity, congenital and acquired heart disease and many endemic NCDs all affect children and/or start in childhood. Children and young people are often targeted by companies advertising fast food, tobacco or alcohol, and many grow up today in environments that are not conducive to them adopting healthy lifestyles (e.g. participating in sport).

Children suffer from a wide range of NCDs: some are triggered in childhood by a complex interaction between the child’s body, surrounding environment, living conditions, infectious agents, nutritional and/or other factors, with consequent scope for preventive action. Some conditions are congenital: each year an estimated 8 million children (6% of all births worldwide) are born

“The Committee [on Economic Social and Cultural Rights] is of the view that a minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights is incumbent upon every State party. Thus, for example, a State party in which any significant number of individuals is deprived of essential foodstuffs, of essential primary health care, of basic shelter and housing, or of the most basic forms of education is, prima facie, failing to discharge its obligations under the Covenant ... In order for a State party to be able to attribute its failure to meet at least its minimum core obligations to a lack of available resources it must demonstrate that every effort has been made to use all resources that are at its disposition in an effort to satisfy, as a matter of priority, those minimum obligations.”

Committee on Economic, Social and Cultural Rights, General Comment 3, The nature of States parties’ obligations, 1991, UN Doc E/1991/23.



Acknowledgement:  
International Insulin  
Foundation

“We now have an opportunity to achieve real, lasting progress – because global leaders increasingly recognise that the health of women and children is the key to progress on all development goals.”

Ban Ki-moon, United Nations Secretary-General: *The Global Strategy for Women’s and Children’s Health*, 6 August 2010.

with a serious birth defect or symptomatic genetic abnormality<sup>8</sup>, and heart defects alone contribute about one-third to one-quarter of all birth defects<sup>9</sup>. The cause of some NCDs – such as some of the pediatric cancers – are not yet well understood.

NCDs are a major cause of preventable mortality, morbidity and disability amongst children in Low- and Middle-Income Countries (LMICs). Many affected children die prematurely because of late diagnosis and/or lack of access to appropriate treatment; those fortunate to survive often experience significant hardship and disability as a result of living with a chronic health condition that is not optimally managed. It is predicted that the global profile of childhood NCDs in LMICs will continue to emerge as infectious conditions are increasingly brought under control. The WHO reported that total deaths from non-communicable diseases are projected to increase by a further 17% over the next 10 years.<sup>10</sup>

The impact of a growing trend of NCDs has other secondary impacts upon children. In many LMICs where provision of chronic care is under-developed, children growing up in a family where a parent lives with an NCD are likely to experience major economic and social effects. Children can be expected to act as carers for parents who are unwell, or may be expected to work to bring in an income to the family home. Such examples have gross impacts upon a child’s social and educational development. The emotional impact upon a child growing up with a parent with a chronic condition (particularly if that condition becomes palliative), can also be significant if they are not in receipt of necessary support.

The UN Summit on NCDs offers a timely opportunity for all member states to ensure that their NCD policies are child-friendly.

*NCDs are increasingly being recognised as a barrier to development and achievement of the Millenium Development Goals (MDGs). Reaching the targets for MDG 4 (a two-thirds reduction in under-five mortality) and MDG 5 (a three-quarters reduction in maternal mortality and universal access to reproductive health) would mean saving the lives of four million children and about 190,000 women in 2015 alone).*<sup>11</sup>

## TEN KEY REASONS TO INCLUDE CHILDREN IN NCD POLICIES AND DISCUSSION:

1. Children are our future, and one of the strongest universal motivators the world has for changing ingrained behaviours
2. Children have a right to health and life, and the international community has guaranteed that “in all actions ... the best interests of the child is a primary consideration”
3. Children can be powerful agents for change and remarkably apt peer educators. Young people should be included in planning and implementation phases of all NCD action
4. Many children have no voice to advocate for themselves. Specific efforts must be made to include them (or their representatives, including parents and families) as a matter of course
5. Children are the cornerstone of a lifecourse approach to the prevention of NCDs
6. The four key shared risk factors commonly associated with adults also have an impact on children: tobacco use; diets high in fat, salt and sugar; physical inactivity; and harmful alcohol intake all affect child health
7. Children are affected by NCDs. Cancer, diabetes, heart disease, asthma, epilepsy, congenital defects and other chronic conditions all affect children
8. There are cost-effective interventions which, if delivered through basic health services during childhood, prevent death and disability and enable children to live long, healthy, productive and fulfilling lives
9. Childhood offers a golden-window of opportunity for cost effective prevention of NCDs. Existing health systems in most low and middle-income countries (LMIC) in particular, are not effectively dealing with the prevention, diagnosis or management of NCDs in childhood
10. Children experience the negative impact of a parent living with an NCD, particularly in LMICs. Forced to provide care or an income for their families, they can experience significant emotional, social and physical consequences

“ Time to deliver on the promise of health and a better future ... for every woman. Every child. ”

Ban Ki-moon, United Nations Secretary-General, Launch of the *Global Strategy for Women's and Children's Health*, 22 September 2010

Acknowledgement:  
World Child Cancer



## 4. A LIFECOURSE APPROACH TO NCD PREVENTION

### PRIMARY PREVENTION

**Primary prevention refers to an action that reduces the risk of a disease developing.**

Action at the very start of the human lifecourse offers the most cost-effective opportunities for preventive action, and there is now strong evidence for the importance of good maternal health, healthy birth weights and breast-feeding to reduce the risk of children developing some NCDs later in adulthood. A skilled birth attendant at every birth is another high priority. When a mother dies at childbirth the risks for child malnutrition (1.6 fold) and underdevelopment are high.<sup>12</sup> Preventable birth asphyxia places the child at increased risk of brain injury<sup>13</sup> and neurodysfunction.<sup>14</sup>

In addition, children's bodies are especially vulnerable to the same risk factors responsible for many of the NCDs that affect adults, and the rate of some of these NCDs amongst children is already on the rise globally, so reducing exposure to risk factors earlier in life will have a substantial impact on the future health of entire populations. A notable example is tobacco use and nicotine addiction, which often start in childhood and early adolescence, leading to increased rates of six of the eight leading causes of death in adults.

Multisectoral and whole-of-government approaches that address the Social Determinants of Health will be essential, with especial focus on: education and awareness raising; youth empowerment in decision making; healthy public policy; strengthening of primary health care; and enforced controls of advertising, marketing and taxation for tobacco, alcohol and unhealthy foods. Although limited data currently exist relating to children and NCD risk factors, there are emerging examples of what can be achieved. The Global School-based Student Health Survey (GSHS) was developed by the WHO in collaboration with UNICEF, UNESCO and UNAIDS, with technical assistance from CDC. It is conducted primarily amongst 13–15 year olds, and provides data on health behaviours and protective factors amongst students that could inform national child-focused efforts to prevent NCDs.<sup>15</sup>

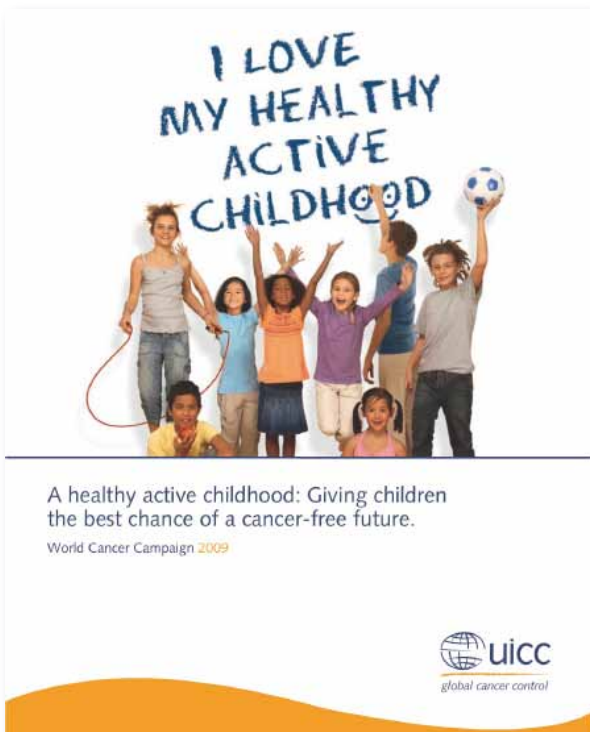
While the UN Summit on NCDs will focus on four key NCDs (cardiovascular disease, diabetes, cancer and chronic respiratory diseases) and risk factors (unhealthy diet, tobacco use, physical inactivity and alcohol abuse), it is important to acknowledge that there are other important preventable non-communicable conditions affecting children which have clearly identified risk factors. Conditions such as Fetal Alcohol Syndrome (FAS), spina bifida and iodine-deficiency hypothyroidism are notable examples, with primary prevention by far the most cost-effective means of reducing the associated disability and death associated.

An integrated approach to the primary prevention of NCDs also makes sense for children and adolescents (just as it does for adults), because there is no clear distinction between the disease paths for some infectious and non-communicable diseases, and health providers concerned about preventing and treating long-term chronic illness should be aware of the connections between the two. Among many examples of this, untreated streptococcus infection in children can progress from rheumatic fever to chronic rheumatic heart disease, which is responsible for at least two percent of all deaths from cardiovascular disease worldwide. Likewise, childhood infections from Epstein-Barr virus have been shown to be a primary cause of Burkitt's Lymphoma; children with the disease often also have malaria infections, which lowers their resistance to the virus. Untreated human papillomavirus infections can become cervical cancer in some adolescents and adults. Sound principles of public health that guide effective prevention and detection of communicable diseases can therefore have major benefit for the prevention of NCDs as well.

## I. UNHEALTHY DIET

Overnutrition and undernutrition often occur in the same communities and even the same families. Malnutrition in utero and in early childhood appears to increase children's vulnerability to overnutrition later in childhood and in adolescence and adulthood, so that prevention of malnutrition during pregnancy and early childhood, particularly the promotion of breastfeeding, are important measures for preventing some NCDs later in life.<sup>16</sup>

Unhealthy diets are associated with overweight and obesity, which rank globally as the fifth leading cause of death. Over 42 million children under the age of five are overweight or obese, which increases their risk of NCDs in adulthood as well as having immediate impact on their health. Of this total, 35 million live in developing countries.<sup>17</sup> Around the world, heavy marketing of foods high in salt, fat, and sugar influence children's food preferences and choices around the world. The onset of obesity during childhood can lead to severe health risks; obesity is a key risk factor for diabetes and cardiovascular disease.



## II. PHYSICAL INACTIVITY

Physical activity is an important protector against a range of NCDs across the lifecourse, and for young people promotes social and psychological well-being, and assists in the development and adoption of healthy behaviours. For children and young people physical activity can come in the form of play, games, sports and other planned and unplanned exercise. The surrounding environment can have a major impact on children's physical activity levels – as can the availability of sedentary activities (such as computer games and television), which compete for children's time and attention.

The WHO has established recommendations for levels of physical activity for all children (regardless of gender, race, ethnicity or income level, but with health care provider consultation for those with disabilities) aged 5-17 years "to improve cardiorespiratory and muscular fitness, bone health, and cardiovascular and metabolic health biomarkers" and they include:

- Children and youth aged 5–17 should accumulate at least 60 minutes of moderate-to-vigorous-intensity physical activity daily.
- Amounts of physical activity greater than 60 minutes provide additional health benefits.
- Most of the daily physical activity should be aerobic. Vigorous-intensity activities should be incorporated, including those that strengthen muscle and bone, at least three times per week.

Acknowledgement: World Health Organisation, Fact Sheet on Young People and diet and physical activity, 2011. Available at [http://www.who.int/dietphysicalactivity/factsheet\\_young\\_people/en/index.html](http://www.who.int/dietphysicalactivity/factsheet_young_people/en/index.html)

**By failing to address under-nutrition, a country may have a 2% lower GDP than it otherwise would.<sup>18</sup> In contrast, investing in children's health leads to high economic returns and offers the best guarantee of a productive workforce in the future.<sup>19</sup>**

**Every year, around eight million children die of preventable causes.<sup>20</sup>**

## RECOMMENDATIONS:

In order to counter the threat of overweight and obesity, governments should:

- Coordinate development of an international code of marketing of foods and beverages to submit to the World Health Assembly by 2013
- Implement broader policy measures that support the WHO Global Strategy on Diet, Physical Exercise and Health
- Ensure all schools and pre-schools comply with standards for food service, education and physical activity. Reverse mentoring of parents (on nutrition, tobacco, alcohol and physical activity and NCDs) is a realistic goal of school health education curriculums
- Develop effective policies and interventions to improve the health, lifestyle choices and nutrition of young women of childbearing age
- Extend access to baby-friendly hospitals (80% of countries by 2015) which support breastfeeding
- Incorporate the International Code of Marking of Breast-milk Substitutes into national legislation (90% of all countries by 2015)
- Implement policies to restrict the promotion and marketing of foods high in saturated fats, trans-fatty acids, free sugars, or salt to children, and improve the availability, affordability and accessibility of fruits and vegetables and other healthy foods
- Incorporate overnutrition into nutrition action plans and programs.

Acknowledgement: IASO (The International Association for the Study of Obesity)

### III. TOBACCO

Worldwide, between 80,000 and 100,000 children start smoking each day, many under the age of 10 years;<sup>21</sup> about 10% of children aged 13-15 smoke cigarettes and about 10% use other tobacco products including waterpipe, bidis, chewing tobacco.<sup>22</sup> The tobacco industry deliberately targets youth by marketing in many ways, including through sports, concerts, and the internet, and the use of flavorings and packaging appealing to children. Raising cigarette taxes effectively reduces youth smoking prevalence: every 10% increase in price reduces the number of children who smoke by 6-7%.<sup>23</sup>

Globally, almost half of all children are exposed to secondhand smoke: 47% in the home and 48% outside the home<sup>24</sup> and more than 150,000 children under five die every year as a result of passive smoking.<sup>25</sup> Children are particularly vulnerable to the effects of secondhand smoke because they are still developing and breathe faster than adults: for children, secondhand smoke is known to cause low birth weight, Sudden Infant Death Syndrome (SIDS), asthma, bronchitis, pneumonia, middle ear infections and an increased risk of developing cancer.<sup>26</sup>

Children are also harmed in less apparent ways; through hunger and malnutrition when scarce resources are diverted to tobacco purchases rather than food, exploitation of children as workers in tobacco farming, and by death and injury resulting from fires caused by cigarettes.<sup>27</sup>

In low-income countries, purchases of tobacco can divert up to 10% of total household expenditures.<sup>28</sup> Money spent on tobacco is not used on basic necessities such as food,<sup>29</sup> education<sup>30</sup> and health care.<sup>31</sup>



Photograph courtesy of the World Health Organisation (WHO)

#### RECOMMENDATIONS:

Accelerate the effective implementation of the Framework Convention on Tobacco Control, especially by:

- increasing taxes
- banning tobacco advertising
- making all public places 100% smoke-free
- banning additives that make cigarettes more attractive to children
- promote smoke-free homes and cars

Acknowledgement: The Framework Convention Alliance (FCA)

### IV. ALCOHOL ABUSE

From conception, the human body is susceptible to the harmful effects of alcohol, and this includes the direct and indirect consequences of alcohol abuse on children in their homes and communities.

Young people experience additional risks. Alcohol consumption is globally responsible for 5% of all deaths of young people between the ages of 15 and 29 years.<sup>32</sup> Trends indicate that alcohol consumption in youth is increasing, particularly the trend to binge drink and becoming intoxicated. This has direct pathological effects on the brain, gut and circulatory system as well as increasing sexual risk-taking behaviour, unintentional injuries and violence.

Acknowledgement: The UK Young Professional Chronic Disease Network

“ The Committee [on the Rights of the Child] is concerned about the influence exerted on adolescent health behaviours by the marketing of unhealthy products and lifestyles. In line with Article 17 of the Convention [on the Rights of the Child], States parties are urged to protect adolescents from information that is harmful to their health and development, while underscoring their right to information and material from diverse national and international sources. States parties are therefore urged to regulate or prohibit information on and marketing of substances such as alcohol and tobacco, particularly when it targets children and adolescents. ”

United Nations Committee on the Rights of the Child, *Adolescent health and development in the context of the Convention on the Rights of the Child*, General Comment No. 4, 1 July 2003.

#### CASE STUDY:

##### Responding to an environment of risk: Youth and NCDs

There is a pressing need to empower and enable young people to make responsible and healthy choices in a world where damaging lifestyle habits are common, increasing, encouraged and even glamorised. This should be done through the integration of education about health within schools and youth groups in which young people can choose alternative ways of spending their money and leisure time.

It is imperative that decisions made at the highest levels regarding young people strive to include young people themselves within decision-making processes. This will bring a better understanding as to their needs and those factors influencing their behaviour and lifestyle choices. Young people must be recognised as active and responsible citizens within society, and supported to adopt healthy behaviours through the promotion of enabling environments.

Acknowledgement: Young Professional Chronic Disease Group, Commonwealth Secretariat

“ Young people are entering the prime of their lives to discover that they are infected with a metabolic ‘virus’ that may lead to cardiovascular disease, diabetes, cancers. They acquired this virus through no real fault of their own, by being exposed to modern lifestyles and unhealthy urban environments. The only way to move forward is to reclaim ownership of how the world and our future are shaped. ”

Dr Amina Aitsi-Selmi, London<sup>33</sup>

## SECONDARY PREVENTION

Secondary prevention refers to the early detection and management of disease so as to avoid serious complications (including disability and death).

Early detection, treatment and care of children and adolescents with NCDs are vital, and have a direct impact on the reduction of preventable disability and death. In childhood, early diagnosis of NCDs usually relies very heavily on the strength of paediatric health systems and general public awareness.

Fortunately, there are some very simple, cost-effective public health measures that can have a major positive impact on NCD health outcomes for children at national and international levels. Newborn screening and educational campaigns are excellent examples.

### I. NEWBORN SCREENING

Newborn screening (NBS) for certain genetic and other congenital disorders that are asymptomatic at birth has existed in many developed countries since the early 1960s. A simple heel prick blood test allows early screening of newborns and diagnosis of detectable conditions, so that catastrophic consequences including intellectual and physical disabilities and death can be minimised with the implementation of early, effective treatment.

Due to its spectacular success and cost-effectiveness, NBS is now a core component of child health care in developed countries. As with vaccination programs, however, work is needed to replicate such services in low income countries. Currently, NBS is nothing more than a consideration in many developing countries. Ironically, this is primarily because of economics – start-up costs prohibit implementation, despite the fact that these relatively inexpensive tests can allow newborns to grow up and participate fully in a society which would otherwise bear large costs associated with their care.

With only about 30% of all newborns globally having an opportunity for any NBS, the opportunities are vast, particularly in Asia, Africa and parts of Latin America. Basic public health infrastructure can be used to build usable screening and follow-up systems. Newborn screening programs in some developing countries have succeeded through integration with birth immunisations already institutionalised in their public health systems. In others, local public health nurses and midwives have collaborated to provide screening services.

Many successful strategies for institutionalising newborn screening in the health systems in developing countries exist and provide usable models for others. Education, innovation and a willingness to provide better health through preventive services are critical components for success. Identifying champions who can lead and learn from experiences of successful programs in other countries is a critical need. Developing countries can least afford to care for children and adults with disabilities that can be prevented by efficient newborn screening programs.

Photograph courtesy of [www.en.wikipedia.org](http://www.en.wikipedia.org)



**SAVE YOUR BABY FROM MENTAL RETARDATION**

Newborn Screening done at birth  
Positive for Congenital Hypothyroidism  
Treated immediately  
Normal 7-year old girl

Newborn Screening not done at birth  
Positive for Congenital Hypothyroidism  
No physical signs at birth  
Not treated immediately  
14-year old retarded boy

**Ask for Newborn Screening**

PHILIPPINES THE DEPARTMENT OF HEALTH & THE NATIONAL INSTITUTES OF HEALTH  
[www.newbornscreening.ph](http://www.newbornscreening.ph)

**Congenital Hypothyroidism (CH) affects about one in every 4,000 newborn babies worldwide (although it is endemic in some low iodine regions) and without treatment results in severe developmental delay. Newborn Screening for Congenital Hypothyroidism is a cost-effective way of preventing disability in children. Treatment with thyroid-replacement tablets is safe, cheap and effective (even in developing countries), and if started early enough children go on to enjoy happy, healthy and productive lives.**

Acknowledgement: Brad L Therrell, National Newborn Screening and Genetics Resource Center, Texas and Carmencita Padilla, Newborn Screening Reference Center, NIH, University of the Philippines, Manila

## II. A FOCUS ON HEALTH WORKERS

Health workers are vital for progress on global health and development, and for ensuring the Millennium Development Goals are met and to facilitate an effective response to NCDs. We share a vision where there is a health worker within reach of everyone, in every community.

Yet, as the UN Secretary-General has noted, the world is suffering from a massive gap of more than 3.5 million health workers. This includes a pressing need for one million community health workers and 350,000 midwives.

Millions more existing health workers lack the support, provision of an adequate living wage, equipment and training they need.

Bold leadership is needed. When governments and major institutions come to meet around the UN General Assembly Meetings in September 2011, we urge them to use the opportunity for a major moment on health workers, by each making new, substantial and specific commitments to expand the number of health workers and better support those workers who are already in place.

To motivate this kind of bold leadership will require a powerful coalition with strong public support. For this reason, a diverse range of organisations have come together with this urgent call for more health workers, better supported. Together we are determined to help inspire a breakthrough on health workers that will save millions of lives.

Acknowledgement: Save the Children Intl

### CASE STUDY: Rheumatic Heart Disease (RHD)

In 2006, a seven year-old Fijian girl came to the district health centre with severe difficulty breathing. In the previous year and a half she had visited the clinic at least ten times with symptoms including a cough, shortness of breath and joint pain, and had been treated for asthma and pneumonia.

A nurse who had just been to a workshop on rheumatic heart disease (RHD) reviewed the medical record and alerted the doctor to the possibility of RHD. Detecting a serious heart murmur, the doctor immediately transferred the child to the nearest referral hospital – too late. The girl died within hours of her arrival there and severe RHD was confirmed post-mortem as the cause of death.



Graduation of the first group of pediatricians from the Nairobi training center in pediatric endocrinology and diabetes, May 2009. Graduates from Kenya, Tanzania, and Nigeria.

Acknowledgement: GPED (Global Pediatric Endocrinology and Diabetes)

The world is suffering from a massive gap of more than 3.5 million health workers. This includes a pressing need for one million community health workers and 350,000 midwives.



Acknowledgement: World Heart Federation

Early detection of rheumatic fever and the heart valve damage it causes (rheumatic heart disease) permits the initiation of the long-term antibiotic prophylaxis that halts progression of RHD. Monthly shots of benzathine penicillin G, a cheap, off-patent antibiotic, would have prevented this and countless other tragic deaths among children living in conditions of extreme poverty.

Since 2005, the Fijian Ministry of Health has developed a national RHD control program with support from the World Heart Federation through its RHD control program in the South Pacific. With technical support from Menzies School of Health Research (Darwin, Australia), the Ministry of Health has established a disease register, trained health workers in disease detection and management, updated guidelines, and piloted systems for continuous quality improvement of RHD control services.

School-based screening by echocardiography has identified hundreds of children in the early stages of RHD, often when it is still too mild to be symptomatic. Now the Ministry of Health is working with Menzies to pilot a model of nurse-led screening by echocardiography designed to determine the feasibility and sustainability of integrating RHD screening into the existing system of school health checks.

Acknowledgement: World Heart Federation

### III. EDUCATIONAL CAMPAIGNS

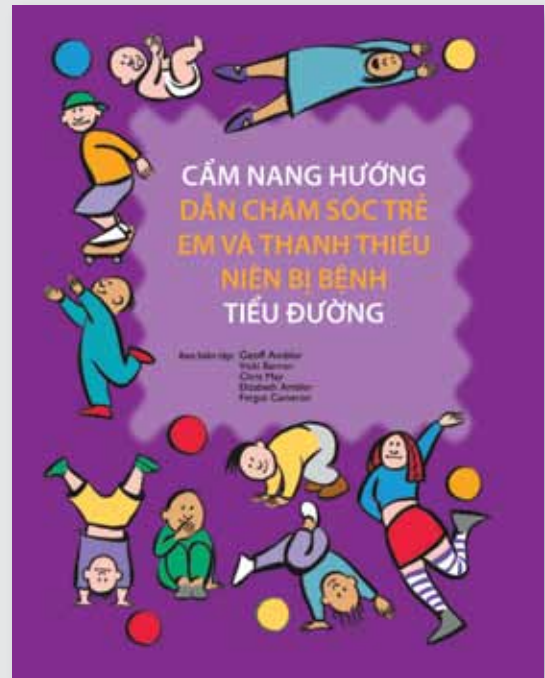
#### Diagnosing diabetes early

A key research project was conducted in Parma Italy in 1999 (Vanelli M et al) on the effectiveness of program to promote early diagnosis of diabetes in children, and prevent serious negative complications associated with late presentation (diabetic ketoacidosis or DKA). In this project, simply displaying posters with a few pictographs and practical messages in primary and secondary public schools coupled with reminders to primary care pediatricians about new onset Type 1 diabetes mellitus significantly reduced the severity of a child's condition at diagnosis (83% DKA at diagnosis in the control group unexposed to the poster project vs 13% in the exposed group).

Acknowledgement: Stuart J Brink, MD: Senior Endocrinologist, New England Diabetes and Endocrinology Center (NEDEC) (Waltham) and Associate Clinical Professor of Pediatrics, Tufts University School of Medicine (Boston) and Past President, International Society for Pediatric and Adolescent Diabetes (ISPAD)



Acknowledgement: ISPAD Members Mauricio Vanelli (Senior Paediatric Endocrinologist in Parma Italy) and Kubendran Pillay (Senior Paediatric Endocrinology Consultant in Durban South Africa)



The cover of the Vietnamese translation of *Caring for Diabetes in Children and Adolescents*. Editors Geoff Ambler and Fergus Cameron

#### Translation of key educational resources

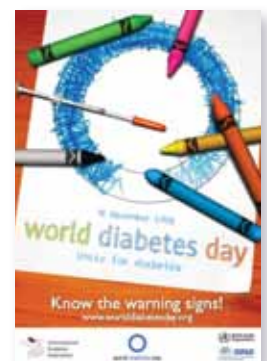
In 2009, the first comprehensive educational resource on Type 1 and Type 2 Diabetes management in children was translated into Vietnamese by CLAN (Caring & Living As Neighbours).

Thanks to generous support from the authors and Novo Nordisk, several thousand copies of this book were printed and made available for use in hospitals and undergraduate medical and nursing schools around Vietnam. As a result, the capacity of health professionals to diagnose and treat Diabetes is improving. Copies were also made freely available to the families of all children currently living with Diabetes.

#### Remembering children on World NCD Awareness Days

World Asthma Day, World Cancer Day, World Diabetes Day and World Heart Day are fantastic opportunities for educating the world. These World Days raise awareness about key NCDs, thereby promoting early diagnosis and access to effective treatment. However, they also have the capacity to remind us of the common underlying risk factors and how we might prevent NCDs in the future.

Used strategically, World Days that remember children are a cost-effective vehicle for spreading key child-focused public health messages to a global audience, prompting all sectors of government (not just health ministers), industry and civil society to get involved and drive lasting change for our future.



## TERTIARY PREVENTION

Tertiary prevention refers to measures taken to reduce the progress and impact of a disease once a diagnosis has been made.

When a child is diagnosed with a chronic health condition, the goal is to help that child enjoy the highest quality of life possible, and thereby enjoy their basic rights to health and a fulfilling existence.

The needs of children with chronic health conditions are complex: they extend beyond the traditional “acute” health context, and involve families, schools and the broader community. Increased capacity of primary, secondary and tertiary health care is required at local and national levels to develop comprehensive chronic care platforms that address the entire lifecourse of humans rather than simplistic silo-approaches to change that risk “forgetting” children, and fail to address the complex and unique health care needs of children. From a purely economic standpoint, children who receive appropriate treatment for their chronic health conditions can go on and make major contributions to society, and return far more than their treatment costs.

### CASE STUDY:

#### A grassroots community development approach to NCDs

Identifying a group of children with the same chronic health condition as a distinct community and visual hub, CLAN (Caring & Living as Neighbours) promotes a community development approach to change, empowering the community to identify key needs and burdens and then work with a range of stakeholders to effect long-term, sustainable change.

**CLAN utilises a strategic framework for action that focuses efforts on five key pillars:**

1. Affordable access to medicine and equipment
2. Education, research and advocacy
3. Optimisation of medical management (primary, secondary and tertiary prevention)
4. Encouragement of family support groups
5. Supporting families to achieve financial independence and escape the financial burdens that result in poverty

Work with Diabetes, Autism, Congenital Adrenal Hyperplasia, Asthma, Epilepsy, Thalassaemia, Hearing Impairment, Cerebral Palsy and Nephrotic Syndrome communities in South East Asia is demonstrating that change is possible when a range of stakeholders come together and ensure the community of children remains the visual hub of all collaborative action.



Strengthening health systems so they have the capacity to meet the needs of children is essential. Many NCDs that affect children are poorly managed within the health systems of low and middle-income countries, with available treatment options inferior even to corresponding adult services. Optimisation of medical management must focus on availability, accessibility, acceptability and quality (AAAQ<sup>34</sup>) within a holistic, patient and family-centred framework.

Integration of child-specific priorities within health systems will be facilitated by the inclusion of chronic and congenital health conditions within IMCI (Integrated Management of Childhood Illness), the WHO Pocketbook of Hospital Care for Children, and other relevant documents and policies.

Not all tertiary care is necessarily expensive and strategic changes to health systems can actually reap cost-benefits results. Ensuring every medication included within the WHO Essential Medicines List for Children is affordably available to all children of the world must be an important global child health priority.

**In 2002, more than 1.2 million people below the age of 20 died from a non communicable disease.**<sup>35</sup>

### CASE STUDY:

#### The value of international cooperation

The Diabetes UK – Mozambique Twinning Project improving diabetes care in a challenging situation. Work by the International Insulin Foundation (IIF), found that in Mozambique in 2003 only 20% of facilities visited had insulin available, 21% had a glucometer and very few healthcare workers were properly trained in diabetes care.

The IIF, following this assessment, collaborated with the Ministry of Health and diabetes association to try to improve the management of diabetes. In 2006, a delegation from Diabetes UK joined the IIF in a visit to Mozambique to see if Diabetes UK could support improvements in diabetes care in Mozambique.

Why should Diabetes UK support diabetes care in Mozambique? One of Diabetes UK's aims is a world without diabetes and its support to Mozambique via the “Twinning Project” would be a way to contribute to this ambitious goal.

From 2007–2009 Diabetes UK supported the following activities in Mozambique:

- Training of healthcare workers
- Development of patient education materials
- Organisation of World Diabetes Day events
- Development of the Mozambican Diabetes Association.

During the audit of the project at the end of 2009, 100% of facilities visited now had insulin and over 80% had glucometers. Besides this the diabetes association developed two new branches and increased its membership 24-fold and increased its activities in supporting and educating people with diabetes.

The association also played an active role in organising activities for World Diabetes Day. The results of this support had a tremendous impact on diabetes care and people with diabetes in Mozambique as all these activities influenced clinical practice as well as general awareness of diabetes.



## 5. CHILD-FOCUSED NCD CASE STUDIES

### DIABETES

#### I. WHAT IS DIABETES?

Type 1 diabetes is one of the most common life-threatening disorders in childhood around the globe, affecting an estimated 486,000 children under 15 years.<sup>36</sup> Insulin injections are required for survival. Close monitoring of blood sugar level, and diabetes education for the child and their family, are also vital for good quality of life, normal growth and development, and avoidance of serious complications.

Type 2 diabetes, the form of diabetes that is very common in adults, is now also increasingly being reported in children across the world. When not properly managed, it results in the same complications as Type 1 diabetes.

#### II. WHAT IMPACT IS DIABETES HAVING ON THE WORLD'S CHILDREN?

In developed countries, children with diabetes generally have full access to care, so they can grow and mature into adulthood and have healthy and productive lives. In contrast in many developing countries, particularly in Sub-Saharan Africa, insulin is often unavailable or unaffordable, and life expectancy for a child with Type 1 diabetes can be as low as one year in resource poor countries, compared to normal life expectancy in the “Western” world.<sup>37</sup>

#### III. WHY ARE CHILDREN IN LOW-INCOME SETTINGS SO VULNERABLE TO THE EFFECTS OF DIABETES?

Access to insulin is usually a major problem for children living with Type 1 diabetes in resource poor settings, but it is not the only barrier to better outcomes.<sup>38</sup>

The cost of care may equate to half or even all of the family's income. Few health professionals know how to manage diabetes in children, and many health facilities are unable to measure a blood glucose level. Some children die as the diabetes has been misdiagnosed as an infection or pneumonia. For those who are diagnosed, many die quickly as insulin and diabetes education are unavailable. Others have inadequate supplies and support and so have poor blood glucose control. They are chronically unwell and develop early and devastating complications – such as kidney failure and blindness – in their early adult life, and are at especial risk of developing tuberculosis if exposed<sup>39</sup>. Many children with diabetes do not finish school, and have difficulty finding employment and marriage partners.

#### IV. HOW CAN WE REDUCE THE BURDEN OF DIABETES ON CHILDREN?

The world is responding to this problem. The International Diabetes Federation Life for a Child Program is working with children's diabetes services in 30 developing countries to improve care and extend coverage to the most under-served communities. Health professional training programs are being conducted by the International Society for Paediatric and Adolescent Diabetes (ISPAD), effective mentoring relationships have been established, and initiatives by other organisations are also underway.

However, much more needs to be done. In each country, the disease should be mapped, the standard of care audited, and registers established. Insulin is an essential drug and as such must be made available in all health centres – it is a travesty that, 90 years



Almost all children with diabetes in Mali used to die quickly. Now, children such as Aïsha and Fatimata can thrive, as insulin is now available and diabetes care is established through the commitment of Malian institutions with support from the International Diabetes Federation Life for a Child Program.

after its discovery, insulin is still not available to all who need it around the world. Health professionals need training in childhood diabetes. Blood glucose testing capacity must be extended so that there is an ability to diagnose diabetes in the acute clinical setting in any health facility (preventing deaths from misdiagnosis). Less expensive equipment for self-blood glucose monitoring is also urgently needed. Training health professionals to effectively manage diabetes will have the added benefit of improving health outcomes for children living with other endocrine conditions as well. No child should die of diabetes.

#### CASE STUDY:

#### Learning from Diabetes – What is needed to strengthen Health Systems for Children?

Based on health system assessments in six countries the International Insulin Foundation (IIF) found that barriers to access to insulin were more to do with problems linked distribution, tendering and government policies than purely accessibility and affordability issues.<sup>40</sup> However, difficulties in accessing insulin were part of the larger problems of accessing proper diabetes care and treatment. These included access to syringes, tools for diagnosis and follow-up, availability of trained healthcare workers, government policies and the role of diabetes associations.

Through the IIF's work what has become apparent is that the supply of insulin alone will not improve outcomes for people with diabetes and governments need to develop a “positive” diabetes environment, which includes:<sup>41</sup>

1. Organisation of the health system
2. Data collection
3. Prevention
4. Diagnostic tools and infrastructure
5. Drug procurement and supply
6. Accessibility and affordability of medicines and care
7. Healthcare workers
8. Adherence issues
9. Patient education and empowerment
10. Community involvement and diabetes associations
11. Positive policy environment.

Improvements have been possible through a structured approach with a clear assessment of the situation, focused recommendations and targeted action framed within an NCD Policy.<sup>42</sup> This helped alleviate health system factors that may act as barriers to proper care. In order for proper adherence, management and outcomes for diabetes and other NCDs in children both the health system and social aspects need to be addressed in a way that is adapted to the country, its health system and culture.

Acknowledgements: Dr. Graham Ogle and Prof. Martin Silink, International Diabetes Federation Life for a Child Program, Sydney, Australia. David Beran, International Insulin Foundation, UK

Each year more than 175,000<sup>43</sup> children are diagnosed with cancer around the world.<sup>44</sup> Perhaps more than any other NCD, childhood cancer is a stark reminder of the human cost of entrenched global health inequities.

### I. WHAT CAUSES CHILDHOOD CANCER?

The cause of many childhood cancers remains unknown, and more research is needed in this field. In the case of some cancers however there are clear infection links. For example, Epstein Barr Virus (EBV) is one of the most common viruses in humans and in children has been related to Hodgkin's lymphoma, Burkitt's lymphoma (the most common cancer among children in Africa, and especially children with chronic malaria), nasopharyngeal carcinoma, and central nervous system lymphomas associated with HIV.

Some childhood cancers are preventable. Child and young adult vaccination programs currently underway in many countries offer protection from Human Papillomavirus (HPV – linked to cervical cancer in young women) and Hepatitis B (associated with liver cancer) and are excellent examples of the value of integrating children within NCD policies.

### II. WHAT IMPACT IS CANCER HAVING ON THE WORLD'S CHILDREN?

In wealthier countries, the majority of children with cancer receive prompt, effective and complete treatment and most are likely to be cured: only 12% of the children in Canada who are diagnosed with cancer will die.<sup>45</sup> Investing in cancer treatment for children gives them the opportunity to lead healthy and productive lives, and also offers high economic returns on the initial cost of treatment.

Unfortunately however, a massive 85% of all children diagnosed with cancer live in developing countries. Children in developing countries who are diagnosed with cancer are virtually given a death sentence: an estimated 90% of children in the 25 poorest countries of the world unlucky enough to be diagnosed with cancer will die.<sup>46</sup>

Acknowledgement:  
World Child Cancer



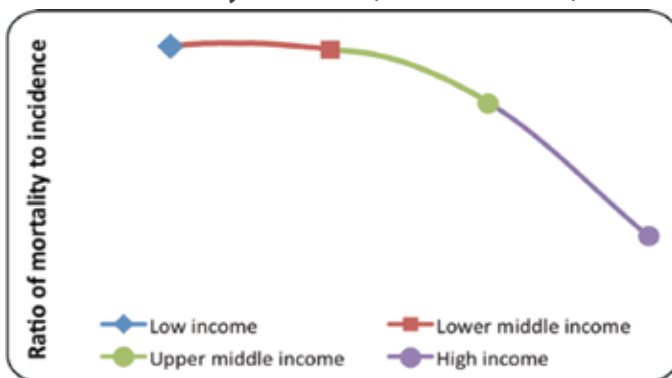
### III. WHY ARE CHILDREN IN LOW-INCOME SETTINGS SO VULNERABLE TO CANCER?

For children with cancer who live in resource-poor countries, access to information; early detection; accurate diagnosis; and effective, affordable treatment are all major barriers to survival. More than one in two of the children diagnosed with cancer in resource-poor countries will die.

Despite the glaring global inequities (see graph), childhood cancers in lower and middle-income countries receive little attention from researchers and health authorities. Among five to 14-year olds, cancer is the: number two cause of death in wealthy countries, number three cause of death in upper-middle income countries, number four cause of death in lower middle-income countries, and number eight cause of death in low-income countries.<sup>47</sup> Infectious diseases are still a major cause of death and disability amongst children in low-income countries and understandably still require significant attention. As countries develop and economies transition however, the pressure to strengthen pediatric health services to effectively manage cancer and reduce the burden of NCDs in children is increased.

Note: Case fatality (calculated by approximation from the ratio of mortality to incidence in a specific year) is much lower in high-income countries than in low-income countries for cancers that are treatable, such as childhood leukaemia (0.26 vs 0.78) and testicular cancer (0.05 vs 0.47), treatable if detected early, such as breast cancer (0.24 vs 0.48), or preventable, such as cervical cancer (0.37 vs 0.63). Estimates are based on International Agency for Research on Cancer GLOBOCAN data for 2008 (<http://globocan.iarc.fr>).3,6. Calculations by Knaul, Arreola-Ornelas and Méndez. Mexican Health Foundation

Ratio of Mortality to Incidence, ALL children 0-14, 2008



### IV. HOW CAN WE REDUCE THE BURDEN OF CANCER ON CHILDREN?

There are a growing number of innovative programs that effectively address the challenge of treating childhood cancers in developing countries in spite of constrained resources. These can and have been replicated around the world. For example, St Jude Children's Research Hospital's International Outreach Program has partnerships with 15 countries that provide mentoring, consultation of clinical services, education and research to strengthen children's cancer services in resource-poor countries.<sup>48</sup>

There are also low-cost drugs that, if made available, could greatly increase children's survival rates. For example, Burkitt's lymphoma, which is the most common childhood cancer in parts of Africa is potentially curable at accost of only \$50US per patient, with a generic drug that has a 50% cure rate.<sup>49</sup>

Some cancers (such as retinoblastoma) are very easy to detect at an early and curable stage. An INCTR-TUCCA public service announcement developed in Brazil and since translated into several languages, is a good example of the simple message of using a flash light to detect this cancer, avoid blindness and save lives.<sup>50</sup>

Creative health financing and insurance schemes (such as Seguro Popular in Mexico) which cover the cost of treating all childhood cancers have resulted in marked increases in adherence to treatment.<sup>51</sup>

## CASE STUDY:

### Pain and palliative care for children with cancer

“No child should die unnecessarily without care” and certainly “no child should suffer” if we have the means to prevent it.

We do know how to help, but far too often that help is not applied! The WHO defines Palliative Care for children as “the total care of the child’s body, mind and spirit” and “also involves giving support to the family”. Palliative care begins when illness is diagnosed and continues irrespective of whether or not a child receives disease directed therapy” in any potentially life limiting illness.<sup>52</sup>

Symptom control is critical because there is always uncertainty about outcome in life threatening conditions.<sup>53</sup> HIV/AIDS and malignancy have been shown worldwide to be the two commonest causes of mortality appropriate to need palliative care.<sup>54</sup>

The most important and prevalent symptoms requiring control are:

- Fatigue and weakness
- Pain
- Anorexia and weight loss
- Delirium and agitation
- Breathlessness
- Nausea and vomiting
- Constipation
- Depression and anxiety
- Excess respiratory tract secretions

A list of 17 Essential drugs has been proposed to address these symptoms, approved but not yet fully ratified by the WHO. Twelve of the 17 are already on the Essential Medicines List for Children (EMLc) albeit seven have new more user friendly formulations, only five are not on the list but should be.<sup>55</sup> Pain control is a major challenge. The World’s 20 richest countries consume 86% of Global therapeutic morphine. In many countries use of opioids is illegal. Reasons given for not using the highly effective WHO analgesic ladder which include opiates are: fear of addiction (unfounded if used properly), excess bureaucracy and stigma associated with prescribing and dispensing, and total reluctance for anyone to take responsibility out of hospitals for safe management.

Consequently, for childhood cancer alone, of the estimated annual new case incidence worldwide of 175,000, at least 100,000 do die (often misdiagnosed), are certainly not offered curative care and rarely, if ever, receive any form of palliative care and in particular no pain relief.

Acknowledgement:  
World Child Cancer



## CASE STUDY:

### Women, Children and NCDs

As the primary carers for children in most parts of the world, women are critical to international efforts to drive change for children who are either at risk of NCDs or living with NCDs.

Unfortunately, women also account for 60% of the world’s poor, and in some countries their lack of access to and control over resources limits their ability to pay for healthcare – most especially for chronic health conditions. Women in low-income families will often prioritise spending on their family’s wellbeing over expenditure on other needs.

It is not uncommon for families to bankrupt themselves in efforts to care for children who have serious health problems. Access to affordable care and health insurance options would reduce this enormous burden on women and families.



“No child should die unnecessarily without care” and certainly “no child should suffer” if we have the means to prevent it.

**Urgent action is required:**

1. **Universal recognition of the palliative care needs of children<sup>56</sup>**
2. **Universal adoption of the WHO definition of palliative care and its application for all children with serious illness**
3. **Rapid approval and dissemination of the Essential Palliative Care Drug List for Children<sup>57</sup>**
4. **Every effort made to ensure universal availability of those essential drugs and the ability to prescribe and dispense them without hindrance and stigma**
5. **Adoption worldwide of the WHO analgesia ladder**
6. **Develop as an essential education component for all student nurses and doctors knowledge on palliative care including for children.**

Acknowledgement: Professor Tim Eden, World Child Cancer/AfrOx

## HEART DISEASE

### I. WHAT IS CONGENITAL HEART DISEASE (CHD)?

Congenital heart disease (CHD) is the most common major birth defect, affecting millions of children around the world. Across the world, approximately one in every 120 children is born with a heart defect – about one million every year. Ninety percent of those babies are born in areas where appropriate medical care is inadequate or unavailable.<sup>58</sup>

### II. WHAT IS RHEUMATIC HEART DISEASE (RHD)?

Worldwide, Rheumatic Heart Disease (RHD), a chronic heart condition caused by rheumatic fever, is the most common acquired heart disease in children. Rheumatic fever is, in turn, an inflammatory disease caused by common streptococcal infections of the throat. RHD can result in irreversible damage to the heart valves, and without surgery and life-long medical treatment the condition is generally fatal or debilitating. Once common in Europe and North America, better living conditions and access to antibiotics have nearly eliminated rheumatic fever in most developed countries, but it remains common among children living in poverty in Africa, Asia and the Pacific and some areas of South America. Now almost exclusively a disease of poverty RHD is estimated to affect at least 15.6 million people, killing 350,000 of them each year<sup>59</sup> – although recent studies suggest that the prevalence could be higher.<sup>60</sup>

### III. WHY ARE CHILDREN IN LOW-INCOME SETTINGS SO VULNERABLE?

Both congenital and acquired heart disease take a heavy toll on children and families in developing countries, particularly those who are extremely poor. Much of acquired heart disease could be averted by the systematic implementation of proven and cost-effective interventions, but a failure to implement these systematically leaves many children and young adults with debilitating and often fatal heart damage that requires complex surgery and life-long medical follow-up. This further increases demands on scarce health resources. Lack of access to skilled medical professionals and appropriate treatment increases the burden of both congenital and acquired heart disease in low- and middle-income countries.

### IV. HOW CAN WE REDUCE THE BURDEN OF HEART DISEASE ON CHILDREN?

Prevention and control of RHD can be delivered through basic primary health services: primary prevention (with early identification and treatment of streptococcal infections that can cause rheumatic fever and subsequent RHD), and systematic secondary prevention protects children who have had rheumatic fever from the recurrences that cause heart damage to progress. Both primary and secondary prevention of RHD require the use of off-patent penicillin. A lack of awareness and political will to ensure systematic preventive services results in disease recurrence and in many children progression to life-threatening heart disease that requires complex surgical and life-long medical care. Those who are less fortunate will succumb to premature death.

Congenital heart disease is treatable: some children need heart surgery, but in many cases early intervention with a one-time procedure will lead to a normal or near-normal life for the child.<sup>61</sup> Due to the lack of pediatric cardiac programs in low- and middle-income countries, many families of children affected by both RHD and congenital heart disease have to travel thousands of miles for surgical treatment and follow up visits. Often, the cost of surgery and follow up care exceeds the annual family income.

Acknowledgement: Children's HeartLink and World Heart Federation

## RECOMMENDATIONS:

Governments should develop and begin to implement plans for:

1. Strengthening their countries' systems of prevention of rheumatic fever and control of rheumatic heart disease systems, so that fewer children will suffer from rheumatic heart disease and the resulting valve damage.
2. Developing or significantly improving their countries' pediatric cardiac screening, diagnosis and treatment systems so that more children will be screened, diagnosed and treated for CHD and RHD at an earlier age.
3. Developing or expanding in-country fellowship opportunities in pediatric cardiology and pediatric cardiac surgery.
4. Increasing investments in children's hospitals and other health care facilities that can safely support pediatric cardiac surgery and post-surgical care for children.
5. Incorporating coverage for pediatric cardiac care in national health insurance schemes.

## CASE STUDY:

### Children and heart disease

Organisations like Heart to Heart International Children's Medical Alliance, Children's HeartLink, and World Heart Federation have supported for many years the development of pediatric cardiac care capacity in underserved areas of the world.

Natalia is seventeen years old. She lives with her parents in a small Russian town and was diagnosed with a relatively common congenital heart defect at six months of age. At that time (in 1993), open heart surgery was rarely performed on babies in Russia. Cardiologists continued to follow her case, conducting periodic echocardiograms to assess her condition.

In October 2010, Natalia was examined in Rostov-on-Don by a team of pediatric heart specialists from Heart to Heart (a twinning project between US and Russian centres). At that stage, Natalia had spent most of the last year in a hospital, recovering from an infection – and desperately hoping to regain enough strength to undergo open heart surgery by the time the visiting Heart to Heart team arrived. She is desperately hoping for surgery that will change her life – or, more to the point, that will save her life.

On 11 October 2010, the joint Heart to Heart-Rostov team was overjoyed to be able to provide Natalia with the life-saving surgery that had eluded her throughout her entire childhood. After her successful operation, everyone involved shared a profound sense of satisfaction and reward – this child could so easily have been lost. Natalia's case is also a sobering reminder that tens of thousands of children of all ages all over the world are still needlessly suffering from highly-treatable heart conditions. Natalia has now transferred to a local junior college, from which she will earn the equivalent of a GED. Then, she will take classes leading to a degree in economics.

Acknowledgement: Heart to Heart International Children's Medical Alliance



## ASTHMA

### I. WHAT IS ASTHMA?

Asthma is a chronic inflammatory disorder of the airways that leads to recurrent episodes of wheezing, breathlessness, tightness in the chest, and coughing, particularly at night or early in the morning. These episodes are usually associated with airflow obstruction within the lungs. Asthma attacks can range in severity from inconvenient to life-threatening. Asthma occurs in all countries regardless of the level of development, although case-fatality rates for children are highest in low and middle-income countries. The prevalence of asthma is increasing in most countries, especially among children.

### II. WHY ARE CHILDREN ESPECIALLY VULNERABLE TO ASTHMA?

Children are different from adults. Due to their anatomy and activity patterns, children breathing the same air as adults get a higher dose of pollutants, and children are more sensitive to the harmful effects of these pollutants. Since children's lungs and immune systems are not fully developed, pollutants can penetrate their lung tissues more easily and cause more damage. Some studies indicate that damage to the lungs early in life can affect lung development and cause permanent changes that may make children more vulnerable to future respiratory problems. Children's airways are also smaller and more reactive to pollutants and irritants than adults' airways. Additionally, children breathe faster than adults, so they take in more pollutants. Finally, children spend up to five times longer outdoors engaging in physical activity than adults do, increasing their exposure to outdoor air pollutants.

### III. HOW CAN WE REDUCE THE BURDEN OF ASTHMA ON CHILDREN?

Reducing the burden of asthma on children will require a broad and comprehensive approach ranging from clinical management to environmental protection. Good clinical management is essential for saving and improving the lives of children with asthma. Quick-relief medications relieve symptoms during an asthma attack while controller medications reduce the underlying inflammation and prevent symptoms, and The International Union Against Tuberculosis and Lung Disease guide for low-income countries, *Management of the child with cough or difficulty breathing* is an excellent example of educational resources that promote quality care.

However, even children with the best clinically managed asthma suffer if they are continuously exposed to environmental triggers. To truly help children with asthma, there also needs to be a focus on reducing environmental contaminants. While scientists continue to explore what causes asthma, it is clear that environmental pollution plays a role in developing and aggravating asthma. Additionally, a number of environmental factors, including air pollutants, environmental tobacco smoke, mold, animal hair, and dust mites can trigger asthma attacks in children who already have asthma.

The strategies for implementing such a broad, clinical and environmental approach must also be comprehensive, ranging from individual treatment, community support, increasing availability of treatment and policy change. Much work can be done at the individual level including providing quality health care, health education, case management, and trigger reduction interventions in the home. Policy change is also necessary to support clinical improvements as well as to provide a long-lasting, far-reaching way to reduce environmental triggers. Policies should reduce exposure to air pollution by improving environmental quality in homes, schools, worksites, and outdoor air.

## RECOMMENDATIONS:

The World Health Organisation developed some program objectives, which could be adopted by all member states. They are as follows:

- surveillance to map the magnitude of asthma, analyse its determinants and monitor trends, with emphasis on poor and disadvantaged populations;
- primary prevention to reduce the level of exposure to common risk factors, particularly tobacco smoke, frequent lower respiratory infections during childhood, and air pollution (indoor, outdoor, and occupational exposure)
- identifying cost-effective interventions, upgrading standards and accessibility of care at different levels of the health care system.

Acknowledgement: RAMP

**Asthma is a serious public health problem throughout the world and the most common chronic disease among children. Worldwide it is estimated that 300 million people have been diagnosed with asthma.**

**The World Health Organisation estimates that 15 million disability-adjusted life years are lost annually due to asthma.**

### CASE STUDY:

#### Indoor air pollution from cookstoves

Cooking and heating with solid fuels such as dung, wood, crop waster or coal leads to indoor air pollution. Exposure is particularly damaging for women and children who spend the majority of their time indoors.

The WHO reported that 56% of all indoor air pollution-attributable deaths occur in children under five years of age.

More than two-thirds of indoor smoke deaths from acute lower respiratory infections in children occur in African and South East Asian Regions and over 50% of the COPD deaths due to indoor air pollution occur in the Western Pacific region.

As a result of cookstove smoke, globally, pneumonia and other acute lower respiratory infections represent the single most important cause of death in children under five years as a result of cookstove smoke.

Acknowledgement: World Health Organisation, Indoor air pollution and health: Fact sheet No. 292, June 2005. Available at <http://www.who.int/mediacentre/factsheets/fs292/en/index.html>

Acknowledgement:  
[www.wikipedia.com/  
wiki/Project\\_Gaia](http://www.wikipedia.com/wiki/Project_Gaia)



## SOME ORGANISATIONS COMMITTED TO INTEGRATING CHILDREN WITHIN THE NCD DISCOURSE WHO HAVE CONTRIBUTED TO THE NCD CHILD WORKING GROUP AND DEVELOPMENT OF THIS DOCUMENT:

**Atfaal Welfare Society** – improving the lives of children living with diabetes and other endocrine conditions in Pakistan.

**Child Lung Health Division of the International Union Against Tuberculosis and Lung Disease** – focused on health services that care for children with asthma and severe lung diseases in low-income countries.

**Children’s HeartLink** – partnering with health care centers in underserved regions to strengthen their capacity to diagnose and treat congenital or acquired heart disease in children

**CLAN (Caring & Living As Neighbours)** – promoting a strategic grassroots, community development framework for action that supports children living with chronic health conditions in resource-poor countries.

**GPED (Global Paediatric Endocrinology & Diabetes)** – representing members from six major regional paediatric endocrinology societies worldwide, GPED is focused on building the capacity of health professionals to care for children with endocrine conditions (including diabetes) in low-income countries.

**Global Task Force on Expanded Access to Cancer Care and Control in Developing Countries** – The GTFCCC is a 28-member task force that combines leaders in cancer and global health. The group has the mandate of designing, implementing and evaluating innovative strategies for expanding access to cancer education, prevention, detection and care in the developing world.

**Heart to Heart International Children’s Medical Alliance** – training physicians internationally in advanced cardiology and cardiac surgery so all children born with heart defects have access to modern heart care.

**International Diabetes Federation** – The International Diabetes Federation (IDF) is an umbrella organisation of over 200 national diabetes associations in over 160 countries. It represents the interests of the growing number of people with diabetes and those at risk. The Federation has been leading the global diabetes community since 1950. IDF’s mission is to promote diabetes care, prevention and a cure worldwide.

**International Insulin Foundation** – provides technical support to improve access to diabetes care and medications in the world’s poorest countries.

**International Network for Cancer Treatment and Research (INCTR / Childhood Cancer)** – building capacity for cancer research and treatment in developing countries.

**International Pediatric Association (IPA)** – an alliance of organisations, with 160 national, regional or sub-speciality pediatric societies as members, all working with other partners to promote physical, mental, and social health for all children, to achieve the highest standards of health for newborns, children, and adolescents in all countries of the world.

**International Society of Paediatric and Adolescent Diabetes (ISPAD)** – organising paediatric diabetes teams from more than a hundred countries, to improve advocacy, education and research on diabetes in children and adolescents

**Life for a Child** – of the International Diabetes Federation (IDF), supporting the care of almost 8000 children living with diabetes in 27 countries worldwide.

**My Child Matters of the UICC (Childhood Cancer)** – building local capacity to reduce inequities in childhood cancer survival in selected resource-constrained countries.

**NCD Child** – putting children on the global Non-Communicable Disease agenda. A project managed by CLAN (Caring & Living As Neighbours) Inc.

**Partners in Health** – providing a preferential option for the poor in health care, by partnering with poor communities to combat disease and poverty.

**Regional Asthma Management & Prevention (RAMP)** – Working together to reduce the burden of asthma.

**Save The Children Intl** – inspiring breakthroughs in the way the world treats children, to achieve immediate and lasting change in their lives.

**St Jude Children’s Research Hospital** – internationally recognised for its pioneering work in finding cures and saving children with cancer and other catastrophic diseases. Founded by late entertainer Danny Thomas and based in Memphis, Tennessee, St Jude freely shares its discoveries with scientific and medical communities around the world. No family ever pays for treatments not covered by insurance, and families without insurance are never asked to pay. St Jude is financially supported by ALSAC, its fundraising organisation.

**The Public Health Institute** – promotes health, wellbeing, and quality of life through research, training, and community building.

**The Young Professional Chronic Disease Network** – harnessing the talents and energies of the next generation of health leaders to collaborate with established stakeholders in the field to battle NCDs

**World Child Cancer** – saving lives and reducing suffering associated with childhood cancer in developing countries by providing world-class expertise, sustained guidance and essential funding.

**World Heart Federation** – working for people around the world to have a longer and better life through the prevention and control of heart disease and stroke.

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## END NOTES:

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# A Focus on Children and Non-Communicable Diseases (NCDs)

The NCD Alliance would like to acknowledge the contribution of **CLAN (Caring & Living As Neighbours)** as Chair of the Child-focused Working Group and for assuming the lead role in the development of this document on Children and NCDs.



Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.

