

30 March 2012

## **SUBMISSION TO THE McKEON REVIEW STRATEGIC REVIEW OF HEALTH AND MEDICAL RESEARCH**

Thank you for the opportunity to provide feedback relating to the review of the health and medical research sector.

SIDS and Kids is a national community based organisation dedicated to saving the lives of babies and children during pregnancy, birth, infancy and childhood and to supporting bereaved families. Established for over thirty years, SIDS and Kids has implemented a Safe Sleeping health promotion program which aims to reduce the risk of Sudden Infant Death Syndrome (SIDS) and fatal sleeping accidents.

The SIDS and Kids movement has had outstanding success in the reduction of SIDS deaths in Australia through the introduction of the evidence-based SIDS and Kids Safe Sleeping program which has achieved a reduction in sudden and unexpected deaths by up to 87% in the last 2 decades. The evidence based approach has been supported by the work of our National Scientific Advisory Group (NSAG) which consists of eminent researchers and health professionals from relevant, diverse fields.

### *Infants and children*

Mortality rates and causes of death are key indicators of the overall general health of a population. For infants and children they reflect individual circumstances surrounding the child's death, and provide insights into social and environmental conditions in which children grow and develop.

Most countries in the world, including Australia, have signed and ratified the UN Convention on the Rights of the Child. By agreeing to undertake the obligations of the Convention, national governments have committed themselves to protecting and ensuring children's rights and to hold themselves accountable for this commitment before the international community. To fulfil obligations pursuant to Article 24 which includes reducing infant and child mortality, State Parties must ensure the provision of necessary health care to children, and ensure appropriate prenatal and postnatal health care for mothers, including the support of breastfeeding.

In addition to the UN Convention, one of the Millennium Development Goals adopted by 189 countries at the UN Millennium Summit in September 2000 is to reduce child mortality. Specifically, Millennium Development Goal Four aims to reduce the Under-Five mortality rate by 2/3 by 2015 compared to 1990 levels. Globally deaths of children under 5 years have reached a record low, falling to approx 8.8 million per year in 2008 compared from almost 13 million in 1990, but still make up 20% of all deaths in the world. Although the under five mortality rate continues to decrease the rate of decline is slowing such that it is unclear whether the target of 31 per 1000 live births can be reached by 2015.

Australia has shown significant progress in reducing infant and child deaths, halving rates between 1986 and 1998, but these have remained comparatively stable to 2006. This is as a result of neonatal intensive care, increased community awareness of the risk factors for sudden infant death, and reductions in vaccine-preventable diseases (AIHW 2009). Australia compares well to other OECD countries however when compared to countries of the same level of industrialisation, Australia does not fare as well primarily due to the higher Indigenous mortality rates, ranking in the bottom third of OECD countries for both infant and child mortality (23rd out of 33) (Australian Institute for Health and Welfare (AIHW) Health line indicators for children's health, development and wellbeing, July 2011).

Aboriginal and Torres Strait Islander children experience significantly worse outcomes compared to non-Indigenous children with 3 times the mortality rate. While children born in remote and socioeconomically disadvantaged areas have double the rate of infant mortality compared to infants born in major cities. The higher mortality rates experienced among these populations is a result of many factors, but largely reflect increased disease prevalence due to reduced access to health care services, high levels of socioeconomic disadvantage, higher rates of disability and behavioural risk factors such as smoking and alcohol consumption (AIHW 2009, p15).

During the period 1997-2006, the three leading causes of infant death in Australia were conditions originating in the perinatal period, congenital anomalies, and symptoms, signs and abnormal finding which include sudden infant death. Perinatal conditions were the leading cause of infant mortality for both Indigenous and non-Indigenous babies, however for Indigenous deaths, signs, symptoms and abnormal findings posed a greater problem than congenital anomalies. This is an important observation as these deaths grouped as other signs, symptoms and abnormal findings contribute to the classification of Sudden Unexpected Deaths in Infancy. In over 95% of sudden infant deaths, there are one or more modifiable risk factors present. This means that if contributing risk factors had been identified and removed the outcome for many infants may not have resulted in death.

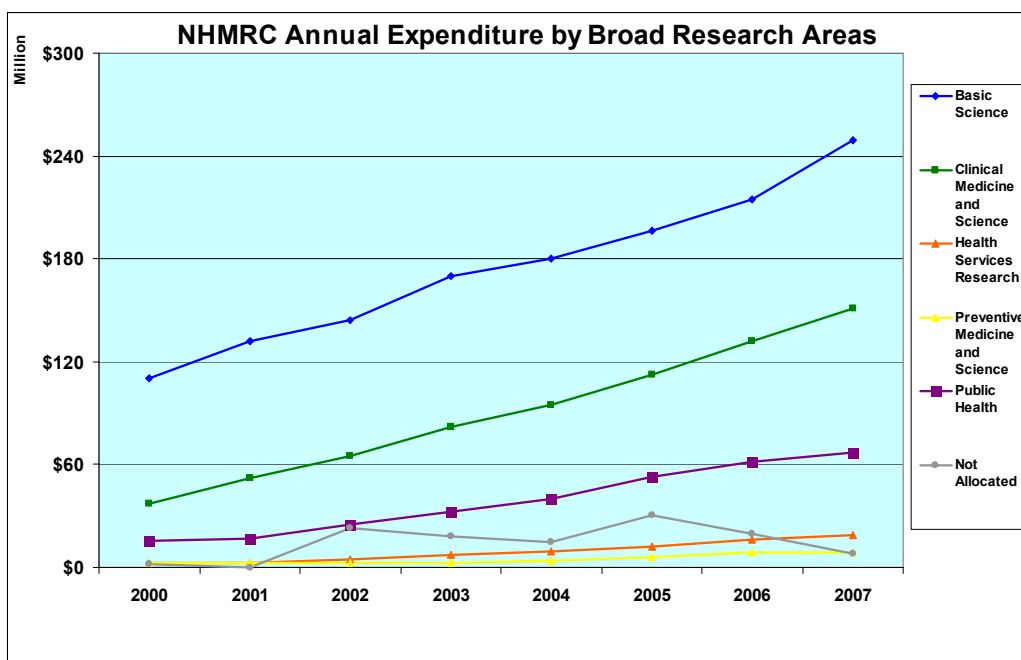
### *Stillbirth*

Each year an estimated 3.2 million stillbirths occur in the last trimester of pregnancy accounting for 1/3 of all perinatal deaths which makes it a problem of continuing public health significance. Despite increasing attention and investment for maternal, newborn and child health, stillbirths remain invisible. Stillbirth is not counted in the Millennium Development Goals. Is not routinely tracked by the UN and is so far invisible in the WHO Global Burden of disease. Birth is the time of the greatest risk with an estimated 1 million intrapartum stillbirths per year. The highest risks for maternal and neonatal mortality are also around the time of birth. Reducing stillbirth directly links to newborn survival which is critical to meeting the child survival MDG and is also a bridge to maternal health goals as many of the same interventions will also reduce the estimated 535,000 maternal deaths each year.

Every year in a Australia, one baby is stillborn for every 135 live births – this means over 2,000 stillborn babies every year in Australia. For every baby that dies of Sudden Infant Death Syndrome (SIDS), 35 are stillborn in Australia. Globally, stillbirths have only declined by 1.1% each year since 1995. As many as two-thirds of stillbirths remain unexplained.

*Health and Medical Research Priorities*

Stillbirth, sudden unexpected deaths in infancy and sudden unexpected deaths in childhood are public health and health service research priorities which deserve further attention. In the last decade, despite Australia's commitment to the UN Convention on the Rights of the Child, the Millennium Development Goals and the Close the Gap campaign (launched in 2007), and the Save the Children campaign launched in 2009, our national funding of health and medical research has not prioritised infant and child mortality, but instead focussed on innovations and the prevention of chronic disease. As can be seen in the NHMRC annual expenditure 2000-2008, proportionately less funding is allocated in this time period to public health and health services research in comparison to Basic Science and Clinical Medicine and Science (Figure 1).



Available from [http://www.nhmrc.gov.au/\\_files\\_nhmrc/file/grants/dataset/trend\\_data.xls](http://www.nhmrc.gov.au/_files_nhmrc/file/grants/dataset/trend_data.xls)

On behalf of the SIDS and Kids and the SIDS and Kids National Scientific Advisory Group we would like to submit the following areas which have been identified as areas of further investigation in order for further reductions in stillbirth, infant and child mortality to be achieved.

### *Stillbirth Research Priority Areas*

Potential interventions for the prevention of stillbirth vary from the time before conception up until labour, and require monitoring through rigorous investigation for their efficacy. These potential measures, as outlined in a recent series on stillbirth published in leading medical journal *The Lancet*, are:

- ❖ Support of autopsy protocols for stillbirth (2/3 of stillbirths remain unexplained)
- ❖ Preconception care to ensure a healthy lifestyle and promote adequate folic acid intake
- ❖ Regular antenatal care including an ultrasound in early pregnancy
- ❖ Folic acid, iron, calcium and vitamin supplementation
- ❖ Fetal monitoring, particularly in regards to fetal movement counting
- ❖ Fetal growth restriction and pregnancy risk screening
- ❖ Early detection and management of diabetes and hypertension
- ❖ Induction of post-term pregnancies as well as consideration of planned caesareans for babies in breech presentation
- ❖ Further investigation of the association between maternal sleep position and risk of stillbirth (specifically left lateral maternal sleep position in the associated reduced risk for stillbirth).
- ❖ Further investigation of the role of infection in stillbirth risk

### *Sudden Unexpected Deaths in Infancy (SUDI)*

- ❖ Case control studies and large cohort population based studies examining risk factors for sudden and unexpected deaths in infancy and in particular the role of breastfeeding, dummy use, infant wrapping and shared sleep surfaces in Australian settings
- ❖ Examination of current risk factors since the Reduce the Risk campaign was launched in Australia is required (no case control studies in Australia since 1980s)
- ❖ Evaluation of uptake of public health recommendations for safe infant sleeping in the Aboriginal, Torres Strait Islander and Culturally and Linguistically Diverse populations.
- ❖ Evaluations of strategies to support role of the extended family including children, young people, elders and parents in reducing risk of SUDI, and building strong, informed communities
- ❖ Investigation of genetic-environment interactions that may play a role in SUDI
- ❖ Evaluation of initiatives that improve uptake of safe sleeping messages in the hard to reach and hard to engage populations: Indigenous families; teenage and young parents; substance using parents, culturally and linguistically diverse groups.
- ❖ Investigations that support use of gold standard pathological investigations conducted using internationally accepted protocols

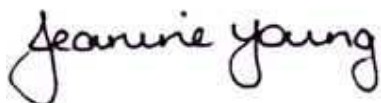
### *Sudden Unexpected Deaths In Childhood*

- ❖ SUDC risk factors, physiology, genetic-environment interactions, family support

Evaluation of best practices in the provision of effective bereavement support for stillbirth, sudden unexpected death in infancy and sudden unexpected death in childhood is also required.

Thankyou for the opportunity to contribute to this important consultation and mapping process for Australian health and research priorities, the outcomes of which should benefit our Australian communities.

Kind regards,

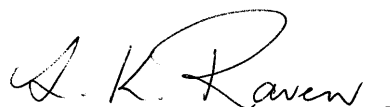


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