



**The Hong Kong Society of
Child Neurology and Developmental Paediatrics**
香港兒童腦科及體智發展學會

Response to the 2008 Healthcare Reform Consultative Document (HRCDD)
of the Health and Food Bureau of the HKSAR Government

By the Hong Kong Society of Child Neurology and Developmental Paediatrics (HKCNDP)

The Hong Kong Society of Child Neurology and Developmental Paediatrics (HKCNDP) is an active professional organization established by professionals from transdisciplinary areas and intersectoral domains dedicated to the advancement of knowledge, betterment of child health services, provision of public health education and promotion of child advocacy for the subspecialties of child neurology and developmental paediatrics. Child health embraces well being in the domains of *medical, social and education*.

On behalf of the Council of the Hong Kong Society of Child Neurology and Developmental Paediatrics (HKCNDP), and representing the welfare of children with neurological and developmental problems in Hong Kong, we would like to submit our response to the Secretary for Food and Health on the Healthcare Reform Consultation Document (HRCDD).

The emphasis of this document has been placed heavily on upcoming financial challenges posed by an ageing population, rising medical costs due to advancement of technology and increasing public expectations. These are indeed facts that should be addressed through responsible reflection, planning and action. We would however like to share with you the perspectives of the children we serve, and how we view the proposals as applied to them.

The document addresses Hong Kong's health and medical needs as a generic group, presumably on the principle that categories of medical and health matters (prevention, ambulatory, hospital, emergency and long term care) apply to the whole population equally. However, children as a group demand different and specific consideration from ethical, logistics and international legal perspectives. In the United Nation's Convention on the Rights of the Child (UNCRC), for which China and Hong Kong are signatories, it is stated that children need a special convention just for them because people under 18 years old often need special care and protection that adults do not. Among the core principles of the convention is the right of the child to life, survival and development. The Convention protects these rights by setting standards in health care; education; and legal, civil and social

services. Furthermore, these rights require not only the existence of the means to fulfill the rights but also access to them. It should be noted additionally that a specific article is present to address the rights of children with disabilities, many of whom are those with chronic neurological or developmental disorders. By agreeing to undertake the obligations of the Convention, national governments have committed themselves to develop and undertake all actions and policies to protect and ensure the stated children's rights, and to hold themselves accountable for this commitment before the international community. These commitments must be carried through in Hong Kong's healthcare for its children, and be among the foundation principles of the present reform proposals.

The package of proposals presented in the HRCD to improve existing healthcare service and market structure has conceptual and logistic value. We are in full support of primary care which focuses on prevention, early intervention, and holistic health care. The setting up of a multi-partite centre of excellence for children that draws on the expertise of both public and private sectors is a subject that Hong Kong has been fighting for our children for decades, and that appears to be finally receiving positive action from the government. Electronic health record systems and other measures that will ensure seamless care over a wide range of health services for our children with complex illnesses and disabilities are not only welcome, but long overdue. For these, HKCNDP has been and will continue to be most willing in providing its support for their implementation and success.

However, on the aspects of public healthcare safety net and financing arrangements, the proposals' application to children is very limited. For children with serious neurological disorders and developmental needs, waiting time and limited coverage of public services are clearly not situations that could be accepted by the public, even if they are successfully contained at the present condition. Not only do these contradict the commitments stipulated by the UNCRC, but counterproductive in logistics, as their negative consequences will bring along economic burdens not only to healthcare, but to society as a whole.

In responding to the proposed financing arrangements, we would first like to highlight the characteristics of children with neurological and developmental disorders.

- a. Many of these children have complex medical issues, often from birth, that affect many aspects of health and development.
- b. Their problems are most often long term, or persistent throughout their life-times.
- c. Families of these children are often seriously disrupted, including financially, as a result of their children's ongoing health issues.
- d. Management of these conditions often requires specialist medical attention with multi-

disciplinary input, only made possible by government sponsored collaborative service models.

- e. Sub-optimal management of these conditions will not only cause serious consequences to these children and their families, but long term burden to the medical system and society as a whole.

With the above caveats, our response to the financial options is as follows.

1. *Out-of-pocket payments* and *Voluntary private health insurance* are clearly unaffordable for almost all parents, given the complex and chronic nature of the children's problems.
2. *Mandatory private health insurance*: There is no element of savings in this option, and thus no protection for their future after their parents stop insurance premium payments.
3. *Social health insurance* means additional tax for those who need to pay tax. Although it allows for choice of services from the private sector. This is only feasible for parents who could afford co-payment, as treatment is often costly because of their sophisticated, intensive or chronic nature. For those who could not afford co-payment, there will be no added value to current system, and parents end up with paying more tax.
4. *Medical savings account*: Medical savings accounts are income linked individual savings accounts. Children should not have to depend on their parents' income level or adequacy of accrued savings for accessing medical care.
5. *Personal healthcare reserve* protects the insured after their retirement through savings. However, even for public services, insurance company will be charged at full costs in the same way as for private sector. In doing so, our clients are likely to exhaust their insurance limit quickly, and will have to co-pay or fall back into the public system. Unless parents can afford heavy additional payments for their treatment, the option will not be viable.

Furthermore, proposed models will only be relevant to these children, many of whom expected to remain dependant over a lifetime, if they continue to be covered by their parents' insurance/savings model, and not planned for falling into a general public safety net upon reaching adulthood. However, the impracticality of this concept, with insurance premiums ceasing as parents age or savings running out, is only too obvious from the start.

IN CONCLUSION, from perspectives of (1) international charters on children's rights for which Hong Kong is bound, (2) characteristics of children with neurological and developmental disorders including complexity, chronicity and serious long term burden if not given timely quality care, and (3) the logistic non-feasibility of proposed financial

arrangement alternatives as discussed, we strongly believe that the Hong Kong government should take on the FULL responsibility in supporting the health and medical care for children with neurological and developmental disabilities, and for ALL OF THE CHILDREN in Hong Kong.

For and on behalf of the Society Council

A handwritten signature in black ink, appearing to read "Chan Chok-wan". The signature is fluid and cursive, with a small flourish at the end.

Dr. CHAN Chok-wan

President, the Hong Kong Society of Child Neurology and Developmental Paediatrics (HKCNDP)

10th June 2008